EVALUATING THE STRUCTURE, PROCESS AND OUTCOME OF AN EARLY INTERVENTION IN PSYCHOSIS PROGRAM: A CASE STUDY OF THE SASKATOON HEALTH REGION

A Thesis Submitted to the College of

Graduate Studies and Research

in Partial Fulfillment of the Requirements

for the Degree of Doctor of Philosophy

in Interdisciplinary Studies

University of Saskatchewan

Saskatoon

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Abstract

This study examines, from an administrative perspective, the structures and processes that support positive outcomes in early psychosis. This examination is undertaken by means of a case study across two eras (1991-1998 and 1999-2006) of early intervention in psychosis care in the Saskatoon Health Region, a Canadian health region with a catchment population of about 300,000. This case study was undertaken using a mixed methods approach, including assessments of early intervention clients, a psychiatrist satisfaction survey, a utilization and cost analysis of emergency room and in-patient care, and focus groups of early intervention program stakeholders. In response to the first study question, the study identified two elements of structure that contribute to the effective provision of early intervention services: a diverse inter-professional team and a ”nested” program model. Next, the study identified one element of structure that detracts from the effective provision of early intervention services: staff stress and burn-out. In response to the second study question, the study identified one element of process that contributes to the effective provision of early intervention services: a strong school outreach and programming component. The study also identified one element of process that detracts from the effective provision of early intervention services: co-morbid substance abuse. In response to the third study question, one key administrative outcome was identified: a reduced cost of in-patient hospital care. It is anticipated the results from this study will assist mid-sized health authorities in meeting the needs of low-incidence and complex client groups.

ACKNOWLEDGMENTS

I would like to express my sincere appreciation to my co-supervisors, Dr. Rein Lepnurm and Dr. David Keegan, for their wisdom, expert knowledge and guidance throughout this study. I would like to thank my committee chairs, Dr. Jon Gillies (1999 – 2005) and Dr. Allen Backman (2005 – 2007). I would like to thank committee members, Dr. Margaret Crossley, Dr. Nazeem Muhajarine, and Prof. Cindy Peternelj-Taylor, for their collective wisdom, valuable suggestions and critiques. Dr. Paula Goering, University of Toronto, provided a thorough and thoughtful external examination that enhanced this document. I would also like to thank members of the Saskatoon Health Region Early Intervention in Psychosis (EIP) team, Mr. Rob Gentes, Ms. Rose Oxby, Mr. Dale Ziolkosky and other SHR staff who assisted with this study. I would like to acknowledge Ms. Karen Gilleta for her assistance with data collection and entry (EIP and historical clients), Ms. Marje Lepnurm for transcription services for the EIP focus groups, Ms. Sinead McGartland for auditing the focus group data, Ms. Karen Janzen and Elaine Leite for assistance with proofreading and formatting, and Mr. Jake Neufeld and Mr. Robert Blizzard for IT support. Dr. Bryan Schreiner's support of my continuing professional development is acknowledged and appreciated. Posthumous thanks are extended to the late Mrs. Melsie Waldner for her encouragement to "stretch taller and higher." I would like to thank my immediate and extended Morrison-Neufeld family, friends and university colleagues for their encouragement, understanding and flexibility throughout my studies. Finally, admiration and thanks are extended to the EIP clients and their families: they make it all worthwhile.

For Melsie

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The following abbreviations are used:

ACM Assertive Case Management

ACT Active Community Treatment

CMHC Community Mental Health Centre

CMHS Center for Mental Health Services (United States)

COPE Centre of Prevention and Evaluation (Manhattan, NY)

DAI Drug Attitude Inventory

DUP Duration of Untreated Psychosis

EIP Early Intervention Program

EIS Early Intervention Service (Birmingham, UK)

EPPIC Early Psychosis Prevention and Intervention Centre

GAF Global Assessment of Functioning

GARF Global Assessment of Relational Functioning

ICM Intensive Case Management

LOS Length of stay

MFG Multiple Family Group

PANSS Positive and Negative Syndrome Scale

PBIQ Person Beliefs about Illness Questionnaire

PEPP Prevention and Early Intervention Program for Psychosis (London, ON)

SAFE Southern Area First Episode

SHR Saskatoon Health Region

SOFAS Social and Occupational Functioning Scale

SVMHS St. Vincent's Mental Health Service (Melbourne, Australia)

1.0 INTRODUCTION

Chapter 1.0 presents an overview of the study, including its origin and relevance. It discusses the characteristics of psychosis, the economic and societal burden of mental illness, and the incidence and prevalence of psychosis. It describes the study's foundational elements: structure, process and outcome. It concludes with the statement of study questions.

1.1 Overview

The provision of effective health services, in a financially constrained environment, is a challenge that confronts administrators, health professionals, policy makers and funders alike. Within this demanding environment, some client[1] groups present added challenges that leave the health system struggling to respond. The severely mentally ill are one such group. Despite treatment advances, these individuals often face lifelong struggles to lead productive lives. One sub-group consists of individuals confronted with first-episode[2] psychosis, a precursor to schizophrenia and other debilitating and chronic psychotic disorders. These disorders are labeled with fear, stigma and superstition that contribute to their devastating impact on the individual, their family, and society (Haber, Hoskins, & Sideleau, 1997).

[1] In this study, the terms *client* and *patient* are used interchangeably.
[2] The first time an individual experiences psychosis is called *first-break* or *first-episode* psychosis. In this study, these two terms are used interchangeably.

Clients who have experienced a first-episode of psychosis represent a mental illness with low incidence yet devastating consequences that has confounded traditional treatment methods. As a result, a pioneering approach known as *Early Intervention in Psychosis* gained recognition throughout the 1990s. While studied extensively from the perspective of psychiatric and mental health practice, less is known about the managerial aspects of successful early intervention services. Consequently, the purpose of this study is to examine, from an interdisciplinary[3] administrative perspective, the structures and processes that support positive outcomes in early psychosis[4]. This examination is undertaken by means of a case study across two eras (1991-1998 and 1999-2006) of early intervention care in the Saskatoon Health Region, a Canadian health region with a catchment population of about 300,000. It is anticipated the results from this study will assist mid-sized health authorities in meeting the needs of low-incidence and complex client groups.

In accordance with University of Saskatchewan guidelines, this dissertation is structured as follows: **Chapter 1** explains the origin and relevance of the study, and introduces the study questions. **Chapter 2** presents a critical review of the relevant literature, focusing on early intervention and its origin and development, description and evaluation. **Chapter 3** outlines the study's preliminary evaluability assessment and introduces the study's Program

[3]An "interdisciplinary" perspective involves studying a subject using multiple viewpoints and methods, while cutting across disciplines. In particular, this study blends health administration and program evaluation with special consideration to three clinical disciplines (nursing, psychiatry and psychology).

[4] For the purpose of this study, early psychosis is defined as a two-year period following a first episode of either non-affective or affective psychosis that occurs in individuals during adolescence or early adulthood (modified from T. Ehmann et al., 2003).

Logic Model. **Chapter 4** articulates the conceptual and analytical frameworks and describes the study's design and methodology. **Chapter 5** presents the local description and context of psychosis care. **Chapter 6** documents the primary study results in relationship to the Goals/Effects in the Program Logic Model and the three dimensions of quality: structure, process and outcome. **Chapter 7** presents the discussion of the results related to the Early Intervention in Psychosis program's structure, process and outcome, within the context of other contemporary research findings. **Chapter 8** summarizes the study's limitations and conclusions, including recommendations for future study.

1.2 Origin of the study

In 1998, Mental Health Services – Saskatoon Health Region (SHR), began developing a new program to treat clients with first-break psychosis. A new model of care, *Early Intervention in Psychosis*, was gaining international recognition, as a result of research and clinical advancements. During this period of development and expansion, mental health researchers and clinicians were beginning to document the theoretical and clinical underpinnings for Early Intervention, including program goals and objectives, descriptions of service delivery, and the use of outcome measures (Edwards & McGorry, 2002). SHR program organizers had the foresight to incorporate an evaluation into the development of the Early Intervention in Psychosis program, an important step often omitted when new programs are designed. Accordingly, they invited the University of Saskatchewan to provide research support for the proposed evaluation, including a review of the program's structure, process and outcome.

This project represented a suitable PhD research study in the area of interdisciplinary health services administration. To this end, a preliminary project proposal was prepared by the prospective doctoral student, under the guidance of her academic supervisor, and was submitted to Interdisciplinary Studies in the College of Graduate Studies and Research, University of Saskatchewan.

1.3 Relevance of the study

1.3.1 Characteristics of psychosis

Psychosis is a serious and debilitating condition that is characterized by defective or lost contact with reality (Nicholi, 1999). It involves a change in a person's perception of reality, including changes in beliefs, information processing, judgment, thinking, and behaviour (American Psychiatric Association 2006). Psychosis can be the first presentation of serious brain dysfunction, such as schizophrenia and other mental disorders (American Psychiatric Association 2006). It severely handicaps the individual's ability to function in social and work situations.

The frequency and severity of symptoms must be present for a significant period of time[5] before a diagnosis of a psychotic disorder can be made (American Psychiatric Association, 2006). This may not be readily apparent in the early stages. According to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (2002), symptoms reported shortly

[5] There is usually a period of time before the detection of acute psychosis, during which individuals may experience anxiety, difficulty functioning, nonspecific physical symptoms, sleep problems and/or social isolation. This somewhat unspecific period is called the illness "prodrome" (Edwards & McGorry, 2002).

before, during and following the first psychotic break often include hallucinations. The person reports seeing and/or hearing things that are not there. The individual may also have delusions (i.e. beliefs that are not based on fact). The delusion may become ingrained to the point that evidence to the contrary will not convince the individual it is not true. Individuals suffering from psychosis often have altered emotions. Sometimes their emotions are blunted while at other times the emotions felt or displayed are completely inappropriate. An example of this would be laughing out loud at a funeral. The blunting of emotion leads the person to be non-reactive in situations where reacting would be expected. The individual often shows decreased motivation for activities that were previously enjoyed as well as increased difficulty remaining focused and "on task." Another commonly reported symptom of psychosis is disorganized thinking. This occurs when the individual's thoughts do not follow a reasonable or logical pattern. A common example of this is schizophasia (commonly referred to as "word salad") in which the person's words come out in random order, and the individual does not realize the word combination does not make sense (Nicholi, 1999).

1.3.2 Economic and societal burden of mental illness

The economic and societal burden of mental illness is substantial and warrants more administrative attention. Health Canada (1998) estimated that the economic burden of mental disorders in Canada was $8.4 billion in 1998 dollars. Direct costs for treating mental disorders totaled $6.3 billion in 1998, consisting of $3.9 billion for hospital care, $887 million for other institutional

care, $854 million for physician care, and $642 million for prescription medications (Stephens & Joubert, 2001). Additional indirect costs, totaling $3.0 billion, consisted of short-term sick days ($866 million), long-term disability ($1,707 million), and premature death ($400 million) (Stephens & Joubert, 2001). Research shows the “largest mental health care expenditure is for schizophrenia due to the high prevalence of this illness, early age of onset, and pattern of chronicity” (Wasylenki, 1994, p. 65). Given this financial landscape, administrators and health providers continue to seek cost-effective models for mental health service delivery.

In addition to the economic impact, mental illness has serious consequences for the individual, their family and society. Literature confirms that psychotic disorders are among the most serious of all psychiatric illnesses, and have severe and far-reaching implications for the individual and their ability to function (Nicholi, 1999). Long-term studies have shown variable outcomes, characterized by high levels of chronicity and disability (McGlashan, 1988). Despite recent advances, the prognosis for these disorders remains poor in many cases. Individuals with psychotic disorders face significant and chronic life challenges.

The extensive toll of psychosis can impair the individual's ability to interact with their social and physical environment. It negatively impacts society's view of the person affected, and creates significant vocational and relationship problems (Gray, 2002). Family members are negatively impacted as they attempt to cope with the individual’s breaks with reality (Mullen, Murray, & Happell, 2002). About half of people with psychosis do not accept or believe

they have the illness, making treatment and follow-up difficult (Pyne, Bean, & Sullivan, 2001).

Studies show that people with schizophrenia and other psychotic disorders are at a higher risk for a multitude of problems: suicide, substance abuse, homelessness, incarceration, employment difficulties and problems with interpersonal relationships. About 40 percent of people with psychosis attempt suicide and of these approximately 25 percent succeed (Palmer, Pankratz, & Bostwick, 2005; Reid, Mason, & Hogan, 1998). Studies confirm that 50 to 80 percent develop a substance abuse problem in their lifetime (Lehman, Myers, & Corty, 2000). As a result, co-morbid substance abuse has emerged as one of the greatest obstacles to the effective treatment of psychotic illness (Dixon, 1999). It is estimated that up to one-third of the homeless have an untreated psychotic disorder (Herrman, 1990; Susser, Struening, & Conover, 1989). Likewise, correctional facilities are over-populated with individuals with psychosis and other severe mental illness (Herrman, McGorry, Mills, & Singh, 1991; Lamb & Weinberger, 1998). It is recognized that many people with psychosis have difficulty achieving and maintaining regular employment (Health Canada, 2002). The illness can delay personality maturation, strain social and family relationships, and place study/career plans on hold (Moller, 2005) When psychosis becomes deeply entrenched, long-term treatment and recovery become even more challenging (Edwards & McGorry, 2002).

It is documented in the literature that people with severe mental illness such as schizophrenia and other psychotic disorders are viewed negatively by society (Gray, 2002). Stigmatization is a barrier to treatment and integration into

the community (Gray, 2002). People with psychosis report feelings and experiences of stigma with a "perceived negative impact on their self-esteem, relationships and job opportunities" (Dinos, Stevens, Serfaty, Weich, & King, 2004, p. 79). Feelings of shame, guilt and blame about having the illness are common (Dinos *et al.*, 2004). The stigma associated with psychosis often has devastating effects on the family as well as the patient. In extreme cases, some individuals are rejected by family and friends, and become socially isolated (Dinos *et al.*, 2004).

Individuals who are receiving treatment for psychosis can often function normally although relapse is common (McFarlane, Link, Dushay, Marchal, & Crilly, 1995). Many experts believe that early intervention is an important strategy for reducing the major economic and societal impact of psychosis (Edwards & McGorry, 2002).

1.3.3 Incidence and prevalence of psychosis

Globally-reported incidence and prevalence rates for psychosis vary widely (Table 1.1), according to a recent Canadian review (Goldner, Hsu, Waraich, & Somers, 2002). This may be attributable, in part, to differences in diagnosis and classification (Goldner *et al.*, 2002).

Statistics Canada reports a Canadian annual incidence rate for psychosis of one per 10,000 (Health Canada, 2002). This would represent about thirty new cases per year in the Saskatoon Health Region. Statistics Canada reports a Canadian lifetime prevalence rate of psychosis of about 1.5 percent of the population, and an active rate of about one percent (Health Canada, 2002). An

epidemiological survey in our neighbouring province of Alberta yielded one-year prevalence rates of four per 1000 of the population for schizophrenic disorders and three per 1000 of the population for the more narrowly defined diagnosis of schizophrenia (Bland, Newman, & Orn, 1988). Cases of protracted drug-induced psychosis related to chronic use of crystalline methamphetamine ("crystal meth") and other drugs are being reported in the literature, a phenomenon that may lead to increased incidence and prevalence of psychosis (Dore & Sweeting, 2006).

Table 1.1 Selection of reported incidence and prevalence rates of schizophrenia and related disorders.

Disorder	**Annual incidence rates**		**Lifetime prevalence rates**	
	Range per 100,000	**Best-estimate per 100,000 (95% CI)**	**Range Per 100**	**Best-estimate per 100 (95% CI)**
Schizophrenia	3.6 – 22.6 *	11.1	.12 – 1.6	.55
Schizophrenic disorders	-	-	0.4 – 2.2	1.45
Schizophreniform disorder	-	-	.06 - .2 **	.11

Source:

Goldner, E., Hsu, L., Waraich, P., & Somers, J. (2002). Prevalence and incidence studies of schizophrenic disorders: A systematic review. *Canadian Journal of Psychiatry, 47*(9), 833-843.

* excludes an outlier, 200 per 100,000 reported in one US study

** excludes outlier, 0 per 100 reported in one Taiwanese study

The incidence of psychosis presents an administrative conundrum for early intervention service delivery in jurisdictions the size of the Saskatoon

Health Region. This low incidence does not produce a sufficient flow of new clients to readily support large-scale early intervention programming. Yet, the prevalence and severity of these disorders, and their grave economic and societal consequences, demand an aggressive, rapid, coordinated and effective health system response.

1.4 Structure, process and outcome

More than 40 years ago, Avedis Donabedian (1966) proposed a model for assessing health care quality. He identified three dimensions of the quality of care: 1) **structure** – characteristics of service delivery (the environment in which health care is provided); 2) **process** – activities that occur between practitioner and patients (the method by which health care is provided); and 3) **outcome** – changes in the patient's current or future health (the consequence of the health care provided). These three dimensions of quality form the basis of the conceptual framework for this study. With respect to early psychosis intervention, structure includes elements such as facilities, staff, funding, and organizational linkages. Process includes elements such as medication management, client and family education, psycho-social training, in-patient care and emergency response. Outcome impacts personal wellness in a variety of areas: emotional, intellectual, physical, social, occupational and spiritual. In the health care environment, cost effectiveness is also considered an administrative outcome.

1.5 Statement of study questions

From an administrative perspective, the study addresses the following three research questions:

Q1. *What elements of structure contribute to (or detract from) the effective provision of early intervention in psychosis services?*

Q2. *What elements of process contribute to (or detract from) the effective provision of early intervention in psychosis services?*

Q3. *What outcome is evident in early intervention in psychosis programming?*

2.0 LITERATURE REVIEW

Studying the structure, process and outcome of early intervention in psychosis services requires an understanding of relevant scholarly literature from a variety of disciplinary perspectives. These dimensions of early intervention are studied and documented by many disciplines including the bio-medical sciences, epidemiology, nursing, psychiatry, psychology, and health administration. This literature review draws to some extent upon all of these discipline-specific viewpoints. The primary database used for this literature search was MEDLINE® (Ovid), 1966 - present. The following search words were used (either alone or in combination): antipsychotic, cost-effectiveness, cost analysis, early psychosis, evaluation studies, family intervention, first-break, first-episode, intervention, medication, outcome, process, prodromal, prodrome, program evaluation, psychoeducation, psychosis, psychotic disorder, psychosocial, quality, schizophrenia, schizoaffective, schizophreniform and structure. Review articles and book chapters were searched to identify additional studies. Reference management was done using Endnote 8.

2.1 Evaluation of mental health services

Evaluation of mental health services is a frequent topic in the evaluation and health care literature. Traditionally, this evaluation has revolved around four primary components: accreditation, practitioner practice standards, quality

management and program evaluation (Hill & Leiper, 1992; Talbott, Hales, & Keill, 1992). The fourth area, program evaluation, is discussed in the following section.

2.1.1 Frameworks and models for mental health evaluation

Over the years, evaluation of mental health services has kept pace with the evolution of service delivery. This change in the mental health field has prompted the development of more effective and appropriate evaluation frameworks and models. A good description of this evolution is presented in the Report of the (US) National Task Force on Mental Health/Mental Retardation compiled by Feldman (1979). In the 1960s and 1970s, the role of program evaluation changed as mental health programs shifted from a "custodial role" to a treatment model. In the custodial setting, the emphasis of evaluation was on minimum program standards, such as provision of adequate food, shelter and clothing. With the transition to a treatment orientation in the late 1970s and 1980s, evaluation started to focus more closely on what is achieved for patients. This included a stronger emphasis on evaluating "the relative effectiveness of alternative methods of care in order to choose among them" (Feldman, 1979, p. 270). Nevertheless, in many cases mental health programs were hesitant to embrace formal evaluation. Given the high demand for patient services, many health care managers were "reluctant to channel money into research and evaluation activities, preferring instead to direct these finite resources toward patient care services" (Feldman, 1979, 272). It was thought that evaluation required too much in terms of "staff resources, equipment and design

sophistication" (Feldman, 1979, p. 272). As a result, the National Task Force concluded that many mental health programs determined that evaluation was not attainable within their finite resources.

The literature is replete with examples of frameworks and models for mental health evaluation. Raskin and colleagues (1996), from the Tulsa (Oklahoma) Institute of Behavioural Sciences, proposed a model for evaluating the effectiveness of intensive outpatient behavioural health care programs. The model consists of five criteria: 1) client selection; 2) program attendance; 3) service utilization and focus of treatment; 4) client improvement; and 5) cost-effectiveness. This program evaluation model was tested with a sample of 285 adults with severe mental illness in a brief hospital-crisis stabilization program. Evaluation data included pre- and post-program measures by clinical staff of clients' symptoms, level of functioning, and "treatment readiness," as well as current and retrospective reports of clients' symptoms based on interviews with clients. Clients' service and financial records were also reviewed. The authors concluded that their evaluation model provides the information necessary to demonstrate program effectiveness. Their results suggest a positive relationship between clinical effectiveness and cost-effectiveness.

Roberts and colleagues (2002) from the University of Kansas proposed a framework for categorizing pediatric psychology research and evaluation into practice and service system process and outcome. The framework addressed the following seven questions: 1) who is being served; 2) what services are provided; 3) how are treatments implemented; 4) what are the outcomes of services; 5) how do various consumers perceive the service; 6) how are

services funded; and 7) what are the alternatives and innovations? Their framework for program evaluation revolves around domains they considered most relevant in child psychology. The domains included 1) diagnostic information on patients; 2) types of intervention; 3) behavioural/psychological outcome variables; 4) costs of treatments; 5) service system functioning; and 6) perceptions of satisfaction from multiple sources. The authors suggest that their comprehensive model for evaluating outcomes in practice and service research can apply not only to services in pediatric psychology, but to other mental health and educational services. They emphasize that "different needs and pragmatic considerations will direct attention to the various components of the framework for different settings and services" (Roberts, Brown, & Puddy, 2002, p. 13).

Hoagwood and colleagues (1996) present a conceptual model of mental health outcomes that broadens the range of "intended consequences of care" for children and adolescents. Their interactive model (called the SFCES model) comprises five domains: 1) symptoms/diagnoses, 2) functioning, 3) consumer perspectives, 4) environmental contexts, and 5) systems. The authors maintain that the model reflects the interaction between the children's evolving capacities and their primary environments (i.e. home, school, and community). They conclude that the research-practice partnership will be strengthened by a more comprehensive view of the impact of care.

In a follow-up study, the Hoagwood team (Jensen, Hoagwood, & Petti, 1996) uses its comprehensive model of outcomes to review the literature to determine the level of knowledge and understanding concerning the outcomes of mental health care for children and adolescents. Despite numerous studies,

the team ascertained that only 38 met their minimum scientific criteria. They generally fell into two categories: 1) focus on the efficacy of treatment(s) for specific disorders or 2) the effectiveness of a particular service or service system. They found only two studies that included outcome assessments across all five SFCES domains.

A local University of Saskatchewan team, Crossley et al. (1997), outlines the “essential ingredients” for the evaluation of a psychiatric day treatment centre. The core components include documentation of client characteristics, behavioural ratings, client satisfaction ratings, discharge status, pre- and post-treatment symptomotology, and follow-up study. Factors critical to successful evaluation include evaluation procedures that meet both clinical and research needs, realistic estimates of time requirements for evaluation tasks and regular feedback sessions with clinical staff.

Bea van Beveren and Hetherington (1997) outlined five front-end steps to effective evaluation of community-based programs: 1) understanding reasons for undertaking the evaluation; 2) securing resources; 3) establishing credibility and enthusiasm; 4) developing consensus about goals and objectives; and 5) observing and fine-tuning the program. They state that there are various interrelated reasons for conducting an evaluation, with many stakeholders interested in the process and outcome. They further state that many community-based programs are struggling for financial resources to maintain operations, thus there may not be the internal expertise, budget or technical resources to produce a scientifically sound evaluation design. They also stressed that it is important that the evaluator develop rapport and good

relationships with staff, and that it is important to create enthusiasm for the evaluation. The authors concluded that it is important to develop organizational consensus about goals and objectives, as a necessary precursor to designing the evaluation protocol.

A study led by University of Washington researcher Srebnik (Srebnik, Hendryx, Stevenson, Caverly, Dyck, & Cauce, 1997) developed a brief and integrated set of reliable and valid outcome measures that could be used by both clients and providers to assess the quality of public mental health care. The team developed a model of outcomes in four domains: 1) client satisfaction; 2) functioning; 3) quality of life; and 4) clinical status. The model was developed from the literature and from the priorities expressed by members of an advisory stakeholder group. Based largely on existing measures, a client survey and a case manager survey were created to assess these domains. A total of 236 adult clients of mental health services from six community mental health centers in Washington State were surveyed. As well, the participants' case managers completed the four-item case manager survey to rate clients' clinical status. Scores and ratings on the survey were analyzed using correlational analysis and principal components analysis to determine whether the data provided empirical support for the four-domain model. The study found that principal components analysis demonstrated support for the four-domain model. Internal consistency of the outcome indicators was adequate, and their concurrent validity was partly supported. The authors concluded that the "described outcome measures provide a practical, empirically supported structure for monitoring and improving public mental health services" (Srebnik *et al.*, 1997, p. 908).

In follow-up to her earlier work, Srebnik (1999) studied service provider perspectives regarding outcome goals of children's day treatment including ideas for how to make day treatment programs successful in achieving stated outcomes. Respondents were direct service staff from 10 day treatment programs in one county in the state of Washington. The primary outcome goals of day treatment reported were: community re-integration, improved adaptive functioning skills, psychological growth, and improved family functioning. Srebnik concluded that the aspects of day treatment that may help achieve outcome targets include: team quality; comprehensive programming; a consistent, safe, accepting program environment; an individualized, developmental approach; linkages with other services; family involvement, and a low staff-to-client ratio.

2.1.2 Large-scale mental health evaluations

Many evaluations of mental health programs described in the literature cover large-scale evaluations of multi-site programs. In 2001, the US Centre for Mental Health Services (CMHS) reported to Congress on the evaluation of the Comprehensive Community Mental Health Services for children and their families. This wide-scale comprehensive evaluation had many facets and phases, and relied primarily on quantitative data. The evaluation used a quasi-experimental design that involved CMHS grant communities, as well as non-funded comparison communities. One phase of the study collected outcome data based on project site evaluations of about 950 children assessed at intake and six months, who were then evaluated for up to 36 months. Outcome

measures used in this evaluation included an assessment of the child's clinical and social functioning, educational performance, living arrangement stability, delinquent activities and engagement by law enforcement, and substance use (Center for Mental Health Services, 2001). Descriptive data including demographic information, diagnostic status, functional characteristics, and referral sources were also collected (Center for Mental Health Services, 2001). Preliminary findings showed improvements for children during their first six months in services. After six months of services, school attendance increased from 67.9 percent to 72.3 percent. Fewer students received failing grades after six months of services, with failing grades falling from 17 percent to 14 percent. In addition, law enforcement contacts were reduced, and fewer youth reported use of cigarettes, alcohol and marijuana. Overall, this study had a strong research design. The evaluators built in a comparison group by using non-funded communities. In addition, they selected useful outcome measures that were relatively easy to obtain. Finally, the large sample size (n=950) assisted in the statistical analysis. This study highlights the importance of selecting outcome measures that are acceptable and conducive to measurement.

Another large-scale evaluation that addresses structure, process and outcome in the field of mental health is described by Garner and Essock (1998). They documented lessons learned in developing and implementing a program evaluation model for a state-wide mental health case management program. The evaluation assessed both process and outcome of standard case management programs and assertive community treatment (ACT) programs for severely and persistently mentally ill adults in Connecticut. The organizing

principles of structure, process and outcome were used to develop the evaluation framework. The pilot phase of their study found that programs varied widely with respect to their capacity to collect the data required in a standard way and to translate these data into indicators. Differences in technical infrastructure accounted for some of this variation, but differences in management styles were also relevant. Data collection challenges persisted and, in the full implementation of the evaluation, only four of the twenty-one ACT programs reported data. The study's authors concluded that it is preferable to start with a modest number of standards to assure more uniform data collection, and to increase them later, as needed.

2.1.3 Out-patient and community-based evaluations

This section reviews literature pertaining to the evaluation of mental health services offered through out-patient and/or community-based services. It lends a useful perspective to the evaluation of early intervention programs, given the similarities in out-patient and community-based programming.

A number of these evaluations focus on treatment outcomes. Bowers (1997) reported on the findings of a review of community care outcomes for the seriously mentally ill, primarily individuals with schizophrenia and affective psychosis, in one health district in the United Kingdom. Severity ratings (based on twelve domains of care) were collected at six-month intervals for two years (n=321), with each domain rated separately on a six-point scale. In addition, satisfaction surveys were conducted of 30 clients and 30 caregivers. The most positive impacts were found in the areas of employment/vocation, finance, self-

care, housekeeping and emotional support. Some areas were found to be far more resistant to change, such as medication compliance, symptoms/course of illness and physical health. The researcher was disappointed to not see more pronounced impact on the clients' symptoms in response to the psychosocial intervention techniques emphasized in the program. Bowers concluded that it was useful to combine the review of problem severity scores with satisfaction survey data.

Holcomb and colleagues (1998) from the University of Missouri - Columbia described a program evaluation to assess treatment outcomes in the areas of quality of life, symptomatology, and levels of functioning for a cohort of out-patients (n=200) one year after they began treatment at a university psychiatric centre. For this evaluation, they used a quasi-experimental design without a control group. Their analysis showed that overall satisfaction with services and staff was directly related to whether the patients reported improvement on the Treatment Outcome Profile. The authors concluded that the Profile showed good sensitivity and predictive validity in revealing statistically significant improvements one year after the patients started treatment.

2.2 Evolution of early intervention in psychosis

2.2.1 Concerns about long-term outcome

In the early 1980s, psychiatric researchers became concerned about the long-term follow-up and outcome of schizophrenia and other psychotic illnesses (Ciompi, 1980; Huber, Gross, Schuttler, & Linz, 1980). Despite the introduction

of psychotropic drugs in the 1950s, a high level of chronicity and disability prevailed (Voruganti, Cortese, Oyewumi, Cernovsky, Zirul, & Awad, 2000). A cloud of uncertainty and pessimism surrounded these disorders. In response, a series of international studies and publications fuelled this dialogue and debate.

One of these early studies, conducted by Huber and colleagues (1980) at the University of Bonn in Germany, studied 502 patients with schizophrenia who had been admitted to a university psychiatric clinic between 1945 and 1959. They were systematically followed from 1967 to 1973. Their average duration of illness was 22.4 years. Twenty-two percent of the patients showed complete psychopathological remission, forty-three percent had “non-characteristic” types of remission, and thirty-five percent suffered from characteristic schizophrenic syndromes. Psychopathological outcome in the patients studied was assessed in relationship to factors such as age at onset, duration of illness, educational level, family history of schizophrenia, personality, social class, and social interaction. The Bonn team concluded that prognostic predictions are possible only when several factors with a similar influence on long-term outcome occur in combination and when factors with a “contrary prognostic influence” are absent. They emphasized that “even under these circumstances, the individual course is by no means certain” (Huber *et al.*, 1980, p. 604).

Around the same time, Swiss-Italian researcher Ciompi (1980) published an account of his investigation of the course of schizophrenia into old age, which included mortality and cause-of-death statistics on 1,642 patients with an average of thirty-seven years of observation. Two hundred and eighty-nine patients survived until the final follow-up examination. The study investigated

the development of schizophrenia, its "psycho-organic" symptoms, and social adaptability. Results showed that the long-term course was favourable in at least half of the cases. Ciompi observed that outcome depended primarily on pre-morbid personality factors and on certain psychopathological factors (such as diagnostic subtype). These findings supported and supplemented the findings of Huber and others[6].

Throughout the 1980s, researchers continued to study the long-term course of schizophrenia. In 1988, McGlashan reviewed ten North American outcome studies of schizophrenia conducted within the past twenty-five years. These studies had a minimum follow-up of ten years. Based on his findings, McGlashan observed that "schizophrenia can be a chronic disease whose outcome on the average is worse than that of other major mental illnesses" (McGlashan, 1988, p. 540). His review showed that schizophrenia is associated with an increased risk of suicide, physical illness, and mortality. He called current treatments "essentially palliative." McGlashan noted that the "course of schizophrenia is not relentlessly progressive, as originally described, but appears to plateau after 5 -10 years" (McGlashan, 1988, p. 540). He described the outcome as "heterogeneous" and attributed much of the variance to sample characteristics, including: 1) expressions of psychopathology (broad vs. narrow diagnostic criteria, subtypes, and co-morbidity); 2) dimensions of chronicity (age of onset, institutionalization, length of illness, and treatment resistance); and 3)

[6] An even earlier study is described in Bleuler, M. T. (1974). The long-term course of the schizophrenic psychoses. *Psychological Medicine, 4*, 244-254.

other predictor variables (gender, marital status, pre-morbid health, and socioeconomic status). McGlashan concluded that chronicity was prevalent and "long-term followup studies have yet to demonstrate clearly any effect of treatment on the natural history of schizophrenia" (McGlashan, 1988, p. 540).

Psychiatric researchers were discouraged by the resistance to treatment, high chronicity and disability identified in these long-term follow-up studies. In response, they started to seek solutions at the other end of the treatment spectrum: first-episode psychosis.

2.2.2 Advent of early intervention

A number of landmark studies propelled early intervention into the mainstream psychiatric literature. British researchers, Eve Johnstone and colleagues (1986), published the preliminary results of the Northwick Park Study of first-episode schizophrenia. The study included 462 patients who were referred over twenty-eight months from nine medical centers for a trial of neuroleptic medication following initial diagnosis of schizophrenia. The 253 patients who met the study criteria were assessed with the Present State Examination, World Health Organization scales for disability, and a rating of "disturbed" behaviour. Their study results showed that "the interval between onset of illness and admission varied widely, and was often more than one year." This period of untreated psychosis was associated with severe behavioural disturbances and family difficulties. They noted that finding appropriate care was often a challenge. The Northwick Park Study team concluded that "current arrangements for initiating management of first

schizophrenic illnesses are frequently unsatisfactory" (Johnstone, Macmillan, Frith, Benn, & Crow, 1990, p. 188).

Yale psychiatrist Ian Falloon (1992) was another researcher to publish a preliminary exploration of early intervention for first-episode schizophrenia. He undertook an uncontrolled study of intensive early intervention with adults who showed signs and symptoms of schizophrenic disorders. The study reported case detection rates that were lower than expected. Falloon suggested that these results "tentatively supported the hypothesis that the initial florid episodes of schizophrenia may be modified when they are detected early and when effective therapeutic strategies are applied with minimal delays" (Falloon, 1992, p. 14). Falloon cautioned that it is difficult to draw any firm conclusions from this preliminary study, and called for further controlled replications of the early intervention approach.

In 1992, Patrick McGorry and colleagues in Melbourne, Australia founded the Early Psychosis Prevention and Intervention Centre (EPPIC) (McGorry 1993). The McGorry team compared outcomes of 51 patients with first-episode psychosis who were treated in the EPPIC program with those of an historical matched control group whose first episode was treated in the "standard program" (prior to establishment of the EPPIC program). After one year, the EPPIC clients had (with all differences statistically significant) a lower number of hospital admissions, shorter length of stay in hospital, lower levels of negative symptoms, lower mean dose of antipsychotic drugs and higher quality of life scores. The EPPIC team concluded that a change in the *timing* and the *content* of initial treatment of psychosis leads to better outcome.

These and other early studies[7] fuelled international interest in the early intervention model. From this point onward, the early intervention in psychosis literature expanded exponentially. Many of these publications discussed the paradigm at a generic level (Birchwood & Macmillan, 1993; McGorry, Edwards, Mihalopoulos, Harrigan, & Jackson, 1996), with considerable research aimed at duration of untreated psychosis, and early intervention treatments and outcomes.

2.2.3 Theoretical foundation: duration of untreated psychosis

As its name implies, the timing of treatment became a primary theoretical underpinning in the development of early psychosis intervention. Early intervention was founded on the premise that longer duration of untreated psychosis adversely impacts the outcome of care (Edwards & McGorry 2002). Harrigan, McGorry et al. (2003, p. 97) summarized that "relatively few predictors of outcome in first-episode psychosis are potentially malleable and duration of untreated psychosis (DUP) is one." Birchwood et al (1998) asserted that this early phase of psychosis, the period when most deterioration occurs, may represent a "critical period" for determining long-term outcome. A considerable body of literature developed around the examination of this theoretical foundation.

[7] Another early study of interest: Johnstone, E., Macmillan, J., Frith, C., Benn, D., & Crow, T. (1990). Further investigation of the predictors of outcome following first schizophrenic episodes. *British Journal of Psychiatry, 157*, 182-189.

To test this hypothesis, Anthony Loebel and team (1992) from Long Island (NY) Jewish-Hillside Medical Center assessed the potential effect of duration of untreated psychosis on outcome in a group of first-episode patients diagnosed with schizophrenia (n=70). Patients received "standardized treatment and uniform assessments" during the acute phase of their illness and throughout the follow-up period (up to three years). Outcome was measured in terms of two factors: 1) time to remission of acute psychotic symptoms and 2) degree of symptom remission. Study results found a mean duration of untreated psychotic symptoms of one year, preceded by a substantial pre-psychotic period. According to their analysis, duration of illness before initial treatment was found to be significantly associated with *time* to remission as well as with *level* of remission. The effect of duration of untreated psychosis on outcome remained significant when diagnosis and gender variables, factors associated with outcome, were controlled. The authors concluded that the duration of psychosis before treatment may be an important predictor of outcome in first-episode schizophrenia. They speculated that acute psychotic symptoms could reflect an "active morbid process which, if not ameliorated by neuroleptic drug treatment, could result in lasting morbidity" (Loebel, Lieberman, Alvir, Mayerhoff, Geisler, & Szymanski, 1992, p. 1187).

Carbone et al. (1999) from the EPPIC program in Melbourne, Australia examined the effect of "phase-specific treatment" on twelve-month outcome for different categories of duration of untreated psychosis (n=250). Their study sample consisted of two "historically sequential cohorts" treated in the same region within different service models, one that was more intensive and phase-

specific (EPPIC). Outcome was compared according to four predefined categories of DUP. Only patients with a mid-range DUP of one to six months who were treated within the phase-specific model experienced significantly better outcomes than patients treated within the previous model. According to the authors, these results suggest that there may be a "limited window of opportunity" in which to influence outcome. These findings were corroborated by Canadian team Malla et al. (2002) in a one year study of the influence of DUP and other predictors on outcome in first episode psychosis. The Malla team found that the rate and level of remission were significantly higher for patients with shorter DUP (<22 weeks). In the Malla study, DUP was the only independent predictor of the level of remission.

A Norwegian study by Larsen et al (2001-b) examined whether duration of untreated psychosis can be shortened in patients with first-episode schizophrenia spectrum disorders and whether shortened duration alters patients' appearance at treatment. Two groups were studied in the same Norwegian health care sector: one from 1993-1994 with usual detection methods (n=43) and one from 1997-1998 with early detection strategies that included education about psychosis (n=66). The early detection teams were modeled after those designed by McGorry and colleagues in Melbourne, Australia. The Norwegian team found that patients with early detection had a shorter median duration of untreated psychosis: 21.5 weeks shorter than patients with usual detection. The number with unspecified psychosis was greater in the early detection group; the number with schizophrenia was less. Early detection patients were younger, had more substance abuse, had better

premorbid adjustment, and were less ill. The authors concluded that early detection of psychosis shortened the duration of untreated psychosis" and it helped patients when they were less severely ill. They summarized: "Given the devastation of psychosis, this is a significant treatment advance" (Larsen, McGlashan, Johannessen, Friis, Guldberg, Haahr, Horneland, Melle, Moe, Opjordsmoen, Simonsen, & Vaglum, 2001-b, p. 1918).

Corroborating these findings, another Canadian study found that untreated psychosis predicts treatment outcome in early psychosis (Black, Peters, Rui, Milliken, Whitehorn, & Kopala, 2001). This Halifax team studied DUP and its association with clinical outcomes in a group of patients with schizophrenia and related psychotic disorders treated in the "naturalistic clinical setting" of the Nova Scotia Early Psychosis Program. For analysis, patients were categorized into a short DUP or long DUP group; the median DUP (57 weeks) was used as the dividing point. At baseline, the two groups did not differ significantly on positive symptoms or total PANSS ratings. However, negative symptoms were more severe in the long DUP group at baseline, and the long DUP group had a significantly higher mean rating for the passive/apathetic social withdrawal item of the PANSS. At six-month follow-up, the long DUP group had significantly higher ratings for positive symptoms and had lower GAF scores. Significantly more long DUP patients had positive psychotic symptoms. The results confirm both the wide range of DUP among patients first presenting with schizophrenia and related psychotic disorders and the association of long DUP, defined as greater than approximately one year, with a poorer clinical outcome. This study supports the view that "patients with a long DUP are likely

to be less responsive to treatment in general and will require greater resources and more intensive interventions" (Black *et al.*, 2001, p. 221). Although the results reported were statistically significant, the study had a very small number of participants: short DUP (n=9) or long DUP (n=10).

However, results on duration of untreated psychosis are not conclusive. Duration of untreated psychosis was not associated with poor outcome in a study by Craig and team (2000). At 24-month follow-up, this team studied patients in the Suffolk County (New York) Psychosis Project who were diagnosed with schizophrenia or schizoaffective disorder (n=155), bipolar disorder with psychotic features (n=119), or major depressive disorder with psychotic features (n=75). Measures at 24-month follow-up included ratings of illness course, Global Assessment of Functioning Scale scores, and current affective and psychotic symptoms. They reported a median duration of untreated psychosis of 98 days for schizophrenia, nine days for psychotic bipolar disorder, and 22 days for psychotic depression. The team concluded that duration of untreated psychosis was not significantly associated with 24-month illness course or clinical outcomes in any of the diagnostic subgroups.

2.2.4 Early intervention: controversy and debate

The field of early psychosis intervention has advanced rapidly as an international movement with far-reaching support (Ehmann, MacEwan, Honer, Bagajewicz, & Tanenberg-Karant, 2004). Nevertheless, an ongoing debate about the value of early intervention has developed (Pelosi & Birchwood, 2003). Not all mental health experts support this approach. One harsh critic called

early psychosis intervention "a waste of valuable resources" encouraged by a small group of "self-confessed evangelists" (Pelosi & Birchwood, 2003, p. 196). Concerns about early intervention revolve around study bias, inappropriate application of general research to early intervention, and ethical concerns about treatment of pre-psychotic[8] individuals. Despite these concerns and criticisms, early psychosis treatment and detection services continue to proliferate with some countries, such as the United Kingdom, moving forward with plans to develop early intervention services nationwide (Pelosi & Birchwood, 2003).

Some early intervention detractors assert that the belief that early intervention in psychosis leads to better outcome may be a result of spontaneous remission. Warren (2005) cautions that patients suffering from a psychosis of recent onset are more likely to experience spontaneous remission and this may explain the results of early intervention studies. He asserts that early intervention research is based on a "misinterpretation of existing data" (Warner, 2005, p. 104). These data appear to show that longer duration of untreated psychosis (DUP) is associated with poorer outcome (Malla, Norman, Ahmed, Scholten, Harricharan, Cortese, & Takhar, 2002). Upon closer examination, critics argue, it is unlikely this association is a direct effect of prolonged psychosis (Warren, 2005). They assert that first episodes of psychosis progress to remission of symptoms in twenty-five to fifty percent of cases (Warren, 2005). Samples of patients with a long duration of illness exclude such "good-prognosis" cases, but samples with a short duration of

[8] Pre-psychotic refers to individuals who are at heightened risk of developing a psychotic disorder but who are not yet symptomatic (Phillips, McGorry, Yung, McGlashan, Cornblatt, & Klosterkotter, 2005).

psychosis will include patients who recover more quickly (Warren, 2005). Warren argues that early detection samples are biased to include more good-prognosis cases and therefore have better overall outcome. In addition, Warren (2005) warns that early intervention patients might be unnecessarily labeled:

> A crucial problem with early intervention in psychosis is that it may mistakenly label and treat the person with a brief psychosis as having a long-term disorder and lock him or her unnecessarily into a career as a psychiatric patient. (p. 106)

Friis and team (2004) examined whether there are systematic differences between early psychosis treatment "refusers" and "consenters" on DUP and/or other admission variables. Of 397 patients in the study, 93 (23 percent) were refusers. The only significant difference was found for DUP. The median DUP for "consenters" was 10 weeks and for "refusers" was 32 weeks. DUP remained significant when all independent variables were controlled. The authors found that DUP was significantly related to risk for refusal. They concluded that this may introduce a type II error bias for studies of the impact of DUP on outcome (i.e. failing to reject the null hypothesis when it is false).

Another concern revolves around the applicability of general research to early intervention. Direct transfer of findings to first episode patients is not always appropriate (Ehmann, Yager, & Hanson, 2003). With respect to antipsychotic therapy, the Ehmann team (2003) concluded that:

> The volume of research specific to first episode psychosis considerably lags the number of studies published on long standing affective and non-affective disorders. The assumption that studies using established illness may be extended to earlier phases of illness and younger patient populations has been adopted frequently in clinical practice. However, this practice may not be wholly defensible on empirical grounds. (p. 33)

In addition, intervention prior to the onset of first-episode psychosis (i.e. during the prodromal phase) raises a number of ethical questions. In a 1997 publication, Yung and McGorry discuss these "logistical" and ethical questions. They reviewed the published literature on prevention of psychotic disorders and other mental disorders, and undertook a critical evaluation of current practice in treating pre-psychotic individuals. Issues arose around the possibility of unnecessary or premature labelling, stigma and treatment. They raised the question of whether early intervention merely diagnoses the disorder earlier but does not actually improve outcome. Yung and McGorry (1997, p. 804) concluded that there are "many legitimate concerns related to intervening in pre-psychotic individuals which must be understood by those involved in planning preventive interventions." They suggested that policies should be developed to address these ethical concerns, and these policies need to be evaluated and changed in response to ongoing research. Notwithstanding, they asserted that these issues "need not stand in the way of the development of innovative preventive approaches to the treatment of schizophrenia and other psychotic disorders" (Yung & McGorry, 1997, p. 804).

Further research into duration of untreated psychosis and the ethical implications of treatment prior to the onset of first-episode psychosis is needed to resolve this divergence of opinion (Norman, Malla, Manchanda, Harricharan, Takhar, & Northcott, 2005).

2.3 Early intervention in psychosis: program components

Proponents assert that early psychosis intervention should constitute "best practice" for this phase of the illness and "not merely the translation of standard treatments developed for later stages and the more persistently ill subgroups of the disorder" (McGorry *et al.*, 1996). Marshal et al. (2004, p.1) called early intervention teams "specialised multi-disciplinary entities that seek to provide a range of sophisticated interventions." In studying expert consensus of the critical elements of early intervention services, Marshal el al (2004) found that these elements fall into 10 broad categories: the clients, team structure, membership of the team, referral and assessment procedures, engaging and maintaining contact, non-pharmaceutical interventions, pharmaceutical interventions, family and significant others, admission to hospital or crisis care, and community connections. Even as early intervention proliferated, the relative importance of these program elements had not been established (McGorry *et al.*, 1996). Nevertheless, most early intervention in psychosis services developed around a common set of program components: treatment with antipsychotic medications; psycho-social treatment of the individual and family; and assertive case management (Edwards & McGorry, 2002; Malla, Norman, Manchanda, McLean, Harricharan, Cortese, Townsend, & Scholten, 2002-b).

2.3.1 Antipsychotic medication therapy

Antipsychotic (neuroleptic) medications have been used since the mid-1950s (Kane & Marder, 1993). Effectiveness in practice has been shown to be substantially less than efficacy in clinical trials, likely due to "patient

heterogeneity, prescribing practices, and noncompliance" (Dixon, Lehman, & Levine, 1995, p. 566). There is consensus that taking antipsychotic medication as prescribed is one of the best methods of managing psychotic symptoms and preventing relapse (Dixon *et al.*, 1995; Perkins, 1999). A number of antipsychotic drugs, called "atypical" or novel antipsychotics (e.g. clozapine, risperidone and olanzapine), were introduced in the 1990s (Dixon *et al.*, 1995). The first of these, clozapine, has been shown to be more effective than conventional antipsychotics (Voruganti *et al.*, 2000). Studies have shown that risperidone and olanzapine are safer than the older drugs and are better tolerated (Voruganti *et al.*, 2000). Research indicates that first-episode patients should be treated rapidly with antipsychotic medication but may benefit from lower dosages (Dixon *et al.*, 1995). In the case of first-episode psychosis, it may be appropriate to "taper or discontinue medication within 6 months to 1 year" (Dixon *et al.*, 1995, p. 568).

Perkins (1999) reported that amongst patients treated with conventional neuroleptics approximately 40 percent stopped taking their antipsychotic medication within one year and about seventy-five percent stopped taking their medication within two years. With conventional neuroleptics, side effects (e.g. weight gain, decreased libido) played a large role in a patient's decision to discontinue antipsychotic therapy. However, Perkins asserted that other factors also have an effect. Perkins presents a health belief model that clinicians can use to assess the relative impact of various factors on medication adherence. This model postulates that "adherence to treatment is determined by the patient's assessment of the perceived benefits of treatment and risks of illness

versus the costs of treatment (including adverse effects such as weight gain)" (Perkins, 1999, p. 25). Other factors include barriers to adherence and "cues to act" such as reminders to take medication. Perkins concluded that patients who believe the risks of treatment outweigh the benefits are likely to discontinue their medication and are candidates for intervention to increase adherence. The health belief model that Perkins advocates is relevant to medication management of atypical antipsychotics as well.

With the advent of the new antipsychotics, it was expected that compliance rates would increase. However, Dolder and colleagues (2002) found adherence rates at six and twelve months were only "moderately higher" in patients who received atypical antipsychotics than in those who received typical agents:

> The cumulative mean gap ratios were 23.2% for typical and 14.1% for atypical antipsychotics at 12 months; thus, patients who received typical agents were without medication for an average of 7 days per month, compared with 4 days per month for those who received atypical agents. At 12 months, compliant fill rates were 50.1% for typical and 54.9% for atypical antipsychotics. (p. 105)

Likewise, the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) investigators, led by Jeffrey A. Lieberman (2005), found that discontinuation rates were similar for conventional and atypical antipsychotics. In this study, the majority of patients with schizophrenia (n=1493) in various groups (atypical versus conventional) discontinued their assigned medication as a result of intolerable side effects or for other reasons. Olanzapine was associated with greater weight gain, but it was the most effective in terms of

discontinuation rate. The efficacy of the conventional antipsychotic agent perphenazine was found to be similar to that of quetiapine, risperidone, and ziprasidone. Given these mixed results, interventions to improve adherence are still warranted even for patients who receive atypical antipsychotic medications (Dolder *et al*., 2002).

Calgary researchers, Coldham, Addington and Addington (2002), studied rates and "correlates of adherence" to antipsychotic medication in first-episode patients. Studying the first 200 admissions to the Calgary Early Psychosis Program, medication adherence was assessed on a three-point scale: non-adherent, inadequately adherent and adherent. They examined family involvement, medication side-effects, substance use, symptoms and quality of life. In their first year in the program, thirty-nine percent of patients were non-adherent, twenty percent inadequately adherent, and forty-one percent adherent. Non-adherent patients demonstrated "more positive symptoms, more relapses, more alcohol and cannabis use, reduced insight, and poorer quality of life" (Coldham, Addington, & Addington, 2002, p. 287). The authors argued that "non-compliance has to be anticipated and relationships maintained with patients and families to intervene as soon as possible to minimize the consequence of non-compliance" (Coldham *et al.*, 2002, p. 289).

For the reasons discussed above, patients may discontinue taking their medication or skip doses, either occasionally or frequently (Perkins, 1999). As a result, management of antipsychotic medications is a key component in early intervention programming.

2.3.2 Psycho-social interventions

McGorry and colleagues (2000) commented that in recent years there has been some “rebalancing” with a move toward greater integration of biological and psycho-social treatments in psychosis. Many psycho-social interventions take the form of psychoeducation for individuals, groups and families.

2.3.2.1 Psychoeducation

McGorry (1995, p. 313) defined psychoeducation as: “the provision of information about mental illness” to patients and their families. Psychoeducational approaches are used to “increase patients' awareness of their illness and its treatment” (Pekkala & Merinder, 2000). Policy makers and funders find psychoeducational interventions particularly attractive because they are inexpensive and relatively easy to deliver (Pekkala & Merinder, 2000).

Finnish researchers Pekkala and Merinder (2000) reviewed the effects of psychoeducational interventions for schizophrenia and related disorders compared to standard education methods. They included all relevant randomized controlled trials involving individuals or groups, with ten studies meeting the study’s inclusion criteria. All reviewed studies of group education included family members. While one study found that compliance with medication was significantly improved (at one year), other studies produced “equivocal or skewed data.” The reviewers found that any type of psychoeducational intervention significantly decreased relapse or readmission rates at nine to eighteen months follow-up compared with standard care. They

cautioned that several of the secondary outcomes (e.g. global level of functioning, knowledge gains, and mental state) were measured using scales that were difficult to interpret. They concluded that (Pekkala & Merinder, 2000):

> Generally, however, findings were consistent with the possibility that psychoeducation has a positive effect on a persons' well being. No impact was found on insight, medication related attitudes or on overall satisfaction with services of patients or relatives but these findings rested on very few studies. Health economic outcome was only measured in one study and data were skewed. It was not possible to analyze whether different duration or formats of psychoeducation influenced effectiveness. (p. 2831)

In summary, Pekkala and Merinder's review found evidence that psychoeducational approaches are useful as part of the treatment plans for people with schizophrenia and related disorders.

2.3.2.2 Family interventions

Family interventions are an important aspect of psychoeducation in early intervention. Core elements of family psychoeducation programs include "the provision of emotional support, education, resources during periods of crisis, and problem-solving skills" (Dixon *et al.*, 1995). Research shows that family interventions play a major role in promoting recovery and preventing relapse following the first psychotic episode (Fadden, 1998; McGorry, 1995). Family interventions in first episode psychosis also aim to reduce the level of distress and burden for the family (Fadden, 1998).

A variety of studies have demonstrated the efficacy of family interventions in psychosis treatment (Fadden 1998; Pekkala & Merinder 2000). The psychoeducational components of family interventions for schizophrenia have been found to reduce relapse and hospitalization rates, and improve treatment

compliance (Fadden 1998). These interventions empower families to air concerns, encourage constructive discussion, and promote opportunities to ask questions within a safe environment (Gleeson, Larsen, & McGorry, 2003). As a result of this evidence, most early intervention services have some aspect of family programming (Edwards & McGorry 2002).

Family education is delivered through a variety of modalities, including multiple family group (MFG) education, single family education or a combined approach. McFarlane and team (1995) compared MFG with education with MFG without education and single family education. They found MFG to be more effective than individual family work in reducing relapse and promoting recovery in schizophrenia. In terms of relapse, the results were similar between MFG with education and MFG without education. This caused them to speculate that the MFG format (rather than the education) increased family problem-solving abilities, reduced stress and anxiety, and promoted more sustained mutual support across the families and clients (McFarlane *et al.*, 1995). According to the authors, this suggests there is a "supportive benefit" for families to meet and interact with other families.

The efficacy of multiple family group education has been evaluated with families of clients with first-episode psychosis (Mullen *et al.*, 2002). The results of the Mullen study suggest that "participants experienced a substantial increase in their perceived understanding of mental illness and their perceived knowledge of treatments for mental illness" (Mullen *et al.*, 2002, p. 227). Study participants increased their understanding of the role of stress in mental illness, their perceived knowledge about the possible causes of mental illness, and their

understanding of prevention strategies. The participants also showed improvement in their knowledge of mental health services and how to access them. Increased comfort in discussing mental health issues with mental health professionals was evident. Rather than relying on family workers, this study highlighted the important role of community mental health nurses in providing family interventions.

In addition to efficacy, family interventions have been shown to have a high degree of family satisfaction. Stanbridge and team (2003) studied families' experiences of services in a clinical setting. In their study, 15 of the first 22 referrals to a Somerset Family Interventions Service agreed to take part in semi-structured interviews regarding family satisfaction and clinical outcome. In spite of initial apprehension regarding family sessions, family members reported “high levels of engagement and satisfaction with the service” (Stanbridge, Burbach, Luca, & Carter, 2003, p. 184). Families thought the sessions helped them deal more effectively with relatives' symptoms and other problems. They especially valued the opportunity for open discussion. They identified positive therapeutic skills such as empathy and non-judgmental approaches to problem-solving. This study emphasized that successful engagement in family work requires referral at an early stage.

Family intervention has an important role to play in early intervention in psychosis given the young age at onset. Mullen and team (2002) emphasize the unique challenges facing this young client group and their families:

> Clients and their families, who are usually both dealing with psychosis for the first time, require a different approach from other client groups. Clients experiencing psychosis for the first time are

> most likely to be between the ages of 16 and 25 years (often living with their parents), so in these circumstances, the routine functioning of the family unit has the potential to be more significantly affected. This is a time where the person is most likely to be in a transition period, moving from adolescence to adulthood and securing their identity and role in society. The experience of psychosis accentuates what is already a period of great change and uncertainty. (p. 226)

2.3.3 Assertive case management

Most early intervention in psychosis programs use some type of assertive case management approach (Edwards & McGorry, 2002). Beginning in the early 1980s, specific models of case management were developed and evaluated (Rapp, 1998). Rapp identified four prominent models of case management: 1) the broker model; 2) the strengths model; 3) the active community treatment model (ACT); and 4) the rehabilitation model. He stated that models of practice are comprised of "assumptions, methods, structures, and tools that dictate the intervention, the ends to which it is committed, and the context in which it operated." Rapp (1998) indicated that while in most respects fidelity seems quite good, models are never "pure" in their replication but are generally modified and adapted. While ACT models differ from Early Intervention in Psychosis by offering an even higher intensity of service (i.e. 24-hour coverage), the case management approaches are similar.

A variety of studies have demonstrated the efficacy of assertive case management. In one such study, Bond and team (1988) examined assertive case management in three community mental health centers (CMHCs) in Indiana. They randomly assigned 167 clients at risk for re-hospitalization to

experimental groups receiving assertive case management (ACM) or to control groups eligible to receive all other aftercare services at the community mental health centers. During a six-month follow-up period, clients received an average of one visit a week from the ACM team, usually in the client's home or in community settings. In two of the three centers, significant re-hospitalization differences were found between ACM and control groups. Overall, ACM clients were re-hospitalized an average of 9.2 days, which was significantly less than the 30.8 days for the controls. No differences were found between groups in quality of life, medication compliance, involvement in CMHC programs, or contacts with the legal system.

Mueser and team (1998) from Dartmouth Medical School in New Hampshire described different models of community care for persons with severe mental illness after reviewing the research literature on case management, including the results of 75 studies. They observed that most research has been conducted on the assertive community treatment (ACT) or intensive case management (ICM) models. They noted that “controlled research on ACT and ICM indicates that these models reduce time in the hospital and improve housing stability, especially among patients who are high service users” (Mueser, Bond, Drake, & Resnick, 1998, p. 73). ACT and ICM appear to have moderate effects on improving symptomatology and quality of life. However, the team concluded that most studies suggest little effect of ACT and ICM on social functioning, arrests and time spent in jail, or vocational functioning.

Overall, the literature shows that assertive case management is associated with reduced time in hospital. Its effect on quality of life and

medication compliance is less clear. Case management remains a fundamental component of most early intervention programming. While bearing some resemblance, it is recognized that evidence for assertive community treatment does not directly translate into evidence for case management in early psychosis intervention due to a number key differences. Notably, most ACT services are offered 24 hours per day, seven days per week (Mueser *et al*., 1998).

2.4 Early intervention: models of care and program descriptions

Edward and McGorry (2002) describe various models of care ranging from the establishment of centers of excellence to “spoke and hub” models where regionalized services are linked to a common hub. In addition, they discuss specialist versus generalist models, and hybrid models. The advantages of a specialist model include separation from patients with more established illnesses, creation of a youth-friendly environment, a team structure that fosters a team philosophy and a dedicated intake service (Edwards & McGorry, 2002). The disadvantages of a specialist model include the requirement for supplementary funding, risk that the specialist service becomes isolated from other services, and the loss of personnel and expertise from the generalist services (Edwards & McGorry, 2002).

During the 1990s, model programs for early intervention in psychosis were developed around the world, mainly in Australia, New Zealand, Europe, the USA (Table 2.1) and Canada (Table 2.2).

Table 2.1 Early intervention in psychosis services selected published accounts of international programs.		
Program	**Location**	**Brief Description**
Birmingham Early Intervention Service	Birmingham, UK	The Birmingham Early Intervention Service (EIS) was launched in 1990 and subsequently developed into a community-based service in 1995. The service provides treatment and support to young people from various racial and cultural backgrounds living in the Birmingham inner city. EIS is offered during the early years of psychosis, beginning with the first psychotic episode. The service provides comprehensive care for three years.
Early Psychosis Prevention and Intervention Centre	Melbourne, Australia	The Early Psychosis Prevention and Intervention Centre (EPPIC) commenced operation in 1992. It is an integrated and comprehensive psychiatric service aimed at addressing the needs of young people with emerging psychotic disorders in the western and northwestern region of Melbourne. Taking a "whole person" approach to mental health service, EPPIC treats young people between the ages of 15-24. EPPIC provides follow-up for 18 months.
Southern Area First Episode (SAFE) Project	New South Wales, Australia	The SAFE project serves a rural population of 182,000 covering 52,000 square kilometres. The project focused on training clinicians

Table 2.1 Early intervention in psychosis services selected published accounts of international programs.

Program	Location	Brief Description
		from each child, adolescent and adult mental health team, with supervision taking place by site visits and teleconferencing. With support of the project team, a "mainstreaming" process was undertaken to train mental health workers, school counsellors and family physicians.
Totara House - Early Intervention in Psychosis Service	Christchurch, New Zealand	Totara House is a specialized multidisciplinary service for young people aged 18-30. At Totara House treatment is provided through: Case management; Group programmes; Family work; Medical intervention; Multi- disciplinary input; and Psychological services.
The Center of Prevention & Evaluation (COPE)	Manhattan, NY USA	COPE is co-managed by the Columbia University Department of Psychiatry and the New York State Psychiatric Institute. It is a clinical research program for young people (ages 12-25) who are at elevated risk for psychosis. COPE offers the following services: Clinical evaluation and consultation; Individual psychotherapy; Support and social groups; Family support and education; Medication evaluation and treatment to reduce symptoms.

Source: Edwards & McGorry (2002), Ehmann, MacEwan & Honer (2004), schizophrenia.com; Welch & Garland (2000)

Table 2.2 Early intervention in psychosis services selected published accounts of programs in Canada.		
Program	**Location**	**Brief Description**
Early Psychosis Program	Calgary, Alberta	The Calgary Early Psychosis Program, a joint program of the Calgary Health Region and the Alberta Mental Health Board, was launched in 1996. It was designed to meet the needs of young people diagnosed with a first episode of psychosis. The Calgary Early Psychosis Program is a three-year outpatient program. Key clinical components include: Case Management; Psychiatric Management; Medication Management; Individual Family Work; Family Group; Individual cognitive-behavioural therapy; and Group Programs.
Prevention and Early Intervention Program for Psychoses (PEPP)	London, Ontario	The PEPP program, founded in 1997, is jointly operated by the London Health Sciences Centre and the University of Western Ontario. Services are predominantly outpatient, plus dedicated beds within a 16-bed inpatient Psychosis Unit in the London Health Sciences Centre. Key clinical components include: Engagement and formation of therapeutic alliance; Case

Table 2.2 Early intervention in psychosis services selected published accounts of programs in Canada.		
Program	**Location**	**Brief Description**
		management; Medical/pharmacological management; Patient and family psychoeducation; Individual cognitive-behavioural therapy; and Group programs.
Psychotic Disorders Clinic, Hamilton Health Sciences	Hamilton, Ontario	Founded in 1990, this clinic serves clients ages 16-65. Clients with psychosis at any phase are admitted. The program is tailored to individual needs of clients at each phase, including early psychosis. Key clinical components include: Comprehensive assessment; Individual psychoeducation and support; Family psychoeducation and support; Negotiated treatment agreements; Low-dose, slow increment antipsychotic medications; Support for reintegration (rehabilitation); and Shared care with family practitioners.
Early Psychosis Programme	Nova Scotia	This early intervention program was established in 1995 as a partnership between the Nova Scotia Hospital and the Department of Psychiatry at Dalhousie University. This service provides assessment and out-patient services to a catchment population of 900,000. Treatment components include antipsychotic therapy,

Table 2.2 Early intervention in psychosis services selected published accounts of programs in Canada.		
Program	**Location**	**Brief Description**
		psychoeducation, counselling, support of vocational and educational activities. The program also offers an eight-week multi-family group and ongoing family support group, with plans for a sibling support group. The service also operates an Early Intervention Mentorship Program (bi-monthly workshops, site visits, and annual conference) for mental health professionals.
Early Psychosis Intervention Clinic (EPIC)	Montreal, Québec	Founded in 1997, this program serves clients ages 17-30. The program is co-sponsored by McGill University Health Centre, Royal Victoria Hospital, and the Allan Memorial Institute. Clinical components include: Establishing a therapeutic alliance; Medical and pharmacological management; Family education and support; Individual cognitive therapy; Individual supportive therapy; Occupational therapy groups; Community-based networks of support.
Prevention through Risk Identification, Management and Education (PRIME)	Toronto, Ontario	PRIME provides early identification and treatment of people ages 14-30 that are at risk of developing psychosis. Services include:

Table 2.2 Early intervention in psychosis services selected published accounts of programs in Canada.

Program	Location	Brief Description
		extensive initial assessments; ongoing follow up assessments; through the medical staff, a range of assessments that include blood tests, neurological and physical examinations; psychiatric consultation; psychiatric management if required; psychotherapy; help with psychosocial issues; and referrals to services that may be more appropriate.

Note: The description of the Saskatoon Health Region, Early Intervention in Psychosis Program is presented in section 5.1.2.

Source: Edwards & McGorry (2002), Ehmann et al. (2004); Whitehorn, Brown, Richard, & Rui, (2002)

2.5 Cost-effectiveness of early intervention in psychosis

Cost studies have received moderate attention in the research literature compared with other aspects of early intervention in psychosis. Nevertheless, the small number of utilization and cost studies of early psychosis intervention is supported by a larger body of cost-effectiveness literature in the areas of community-based mental health, home-based mental health, and assertive/intensive case management.

Rigorous cost analysis of mental health services dates back several decades. Weisbrod (1983) published the first cost-benefit analysis of a controlled (random assignment) experiment in the mental health field. Using a large number of tangible and intangible forms of benefits and costs, he compared a traditional, hospital-based approach to treating mental illness with a nontraditional community-based approach. Weisbrod's results (1983, p. 844) supported the hypothesis that "hospitalization of the mentally ill is, except for emergencies, less effective than community-based treatment of approximately equal cost."

More recently, Carr and his Australian team (2004) studied the predictors of direct and indirect (time-loss) mental health care costs in psychotic disorders. Using structured interview data (n=980) from the Low Prevalence Disorders Study, they examined predictors of the costs of psychosis. Their estimates of annual costs per patient were calculated from the perspectives of government and society. Taking into consideration premorbid, psychosocial and clinical factors, the team assessed their respective contributions to patient costs. The

study found that schizophrenia involved greater costs than other psychotic disorders. Non-completion of high-school and “chronicity of illness course” were predictive of higher costs. Factors such as age at onset and current symptomatology were linked primarily with direct mental health care costs, while factors such as male gender and overall disability were linked with indirect costs. In order to reduce direct and indirect costs, the authors recommended several treatment strategies, including early intervention programs. They advocated for the ongoing evaluation of the cost-effectiveness of these approaches from the perspectives of both government and society.

While not specifically early intervention in psychosis, a Canadian study of a home-based program for the treatment of acute psychosis contained a limited but useful cost analysis (Wasylenki, Gehrs, Goering, & Toner, 1997). The study calculated the program’s operating costs for 60 episodes of patient care. The average number of nursing visits per episode was 48 and the average length of episode was twenty-six days. The direct service Home Treatment Program daily cost was $139.78 (98 percent of which was nursing costs) compared to an institutional per diem cost at the Clarke Institute (Toronto) of $637. On the inpatient unit the average length of patient stay was 28 days. During this time, each patient received the equivalent of eight hours of nursing care each day. This compared to an average of two hours per day in the Home Treatment Program, resulting in a considerably lower nursing care cost in the Home Treatment Program. The authors concluded that the program's cost, in comparison to the Clarke Institute's per diem cost, was “strikingly low.” Nursing care costs, in particular, were reduced and overall savings generated by the

program were substantial. This finding is consistent with other literature on community-based treatment which demonstrates that community care is as effective as hospital care and less costly (Weisbrod, 1983). The Toronto authors cautioned that their cost analysis did not take into consideration other cost dimensions of home treatment and hospital-based care.

Research has shown that intensive case management, a common element in early psychosis intervention, reduces mental health service utilization and costs. Quinlivan and team (1995) in San Diego, CA evaluated the effects of an intensive case management model on clients' use of inpatient and outpatient psychiatric care and on the costs of care. Ninety clients of a county mental health system who were frequent users of inpatient services were randomly assigned to either an intensive case management group, a traditional case management group, or a control group that received no direct services. Outcome variables measured over a two-year period were number of units used by clients and costs of inpatient care in county and private facilities and various types of outpatient care, including day treatment and use of an emergency psychiatric unit. The team found that clients who received intensive case management had fewer inpatient days and reduced overall costs for mental health services. They concluded that assertive outreach and intensive case management can reduce hospitalizations of clients who are frequent users of inpatient care and can reduce overall mental health care costs. These results support the earlier findings of Bond and team (1988) who found that mental health centers in Indiana had six-month savings of about $5,500 (in 1998 dollars) for each Assertive Case Management client compared to a control

group that received the standard aftercare services. These savings were attributed primarily to reduced hospitalization rates.

University of Maryland researchers Scott and Dixon (1995) found similar results when they examined the impact of assertive community treatment (ACT) and case management models on the use of inpatient hospitalization and other community mental health services, costs, and other clinical and social outcomes. ACT programs were found to reduce hospitalization and increase use of community mental health services at an equivalent or reduced cost. In this study, greater fidelity to the ACT model produced better outcomes. The researchers found that the impact of case management models was less consistent, but intensive case management programs were also found to reduce hospitalization and cost.

In follow-up to a clinical outcome study (McGorry 1993), Mihalopoulos, McGorry and Carter (1999), examined the cost-effectiveness of the well-known Early Psychosis Prevention and Intervention Centre (EPPIC) in Melbourne, Australia. Using the perspective of the government funding agency, this cost-effectiveness study compared EPPIC to its precursor service (the "standard program"). Their analysis looked only at direct costs. Results showed that the weighted average cost per patient for the first twelve months was lower (by $7110 AUD[9] per patient), while "treatment outcomes were superior" (Mihalopoulos, McGorry, & Carter, 1999, p. 54). The savings were attributed to the "reduction in in-patient costs outweighing substantial increases in the costs of community care" (p. 54). Overall, the authors concluded that EPPIC was

[9] $7110 AUD @ 1.5494 to USD = $4588 USD @ 1.4858 to CAD = $6818 CAD (in 1999 dollars)

considerably more cost-effective than its precursor. They cautioned that these results, while encouraging in terms of the further development of integrated, phase-specific intervention programs for early psychosis, are not conclusive, and they advocated for further research in the area of cost-effectiveness.

It is generally recognized in the literature that certain subsets of patients, such as those with co-morbid substance abuse, will have greater utilization and costs of mental health service. One such study, undertaken by University of Washington researcher Kivlanhan and team (1991), used retrospective self-report data from 60 outpatients with schizophrenia in a community support program to study the relationship between a history of substance abuse and rate of psychiatric re-hospitalization and outpatient treatment cost. The team reported that the sample showed a significant overall reduction in days spent in a psychiatric hospital (or jail) and in outpatient treatment expenses during the first year in the program. Patients with recent symptoms of substance abuse (n=27) showed consistently smaller reductions than patients with no history of substance abuse (n=17) or patients with no recent substance abuse symptoms (n=16). The only significant difference between the groups was in the total number of days spent in an institution. This study suggests that treatment of patients with concurrent substance abuse and schizophrenia is "disproportionately more costly than that of patients without dual diagnoses" (Kivlahan, Heiman, Wright, Mundt, & Shupe, 1991, p. 613).

These findings were supported by a similar study undertaken by New Hampshire team Bartels et al. (1993). They prospectively measured utilization and cost of institutional and outpatient services over one year for three groups of

patients with schizophrenia: current substance abusers, past substance abusers, and those without a history of substance abuse. The team found that current substance abusers had significantly greater utilization and cost of institutional (hospital and jail) services as well as greater utilization of emergency services. They did not find significant differences between the groups in utilization and cost of other services, including psychosocial rehabilitation, outpatient treatment (case management, psychotherapy, and psychiatric visits), and housing supports. They affirmed the challenges for developing cost-effective treatments for dually diagnosed individuals.

More recently, Goldberg and colleagues (2006) evaluated the service use and hospitals costs of first episode patients in London, Ontario during two periods of time: pre-early intervention program - 1993 to 1995 (n=146) and post-early intervention program - 1997 to 1999 (n=159). Over the two years following the introduction of the new service, the EIP patients had significantly fewer admissions to a regular psychiatric in-patient service and made significantly fewer visits to the emergency department. There was a significant reduction in mean cost per case (regular bed use) of $1028 to $792, and there was a significant reduction in the mean cost of emergency visits from $519 to $353. However, time series analysis could not attribute this change to the introduction of the early intervention service. The authors called for further study to evaluate the cost-benefit of early intervention services.

On the whole, studies have found early intervention (and its elements such as assertive case management) to be more cost-effective than the traditional approach to care primarily as a result of the reduction in in-patient

costs. Most studies have looked at direct costs (primarily nursing care and hospitalization), while others have also considered in-direct (e.g. time-loss) costs. Researchers speculated that even greater advances, including improved outcomes and reduced costs, could be achieved with a move from a secondary prevention[10] to a primary prevention[11] model (McGorry, Yung, Phillips, Yuen, Francey, Cosgrave, Germano, Bravin, McDonald, Blair, Adlard, & Jacks, 2002).

2.6 Prevention of psychosis in the prodromal phase

As the early intervention model matured, psychosis researchers started to recognize the importance of prevention of psychosis in the initial prodromal phase (defined as the period of disturbance preceding a first psychotic episode) (Yung & McGorry, 1996).

To inform this discussion, Yung and McGorry (1996) reviewed the literature on prodrome, including descriptions of signs and symptoms, and patterns/durations of prodromes in both schizophrenic and affective psychoses. They compared early detailed descriptions (achieved mainly through anecdotal reports) with contemporary conceptualizations (such as the DSM-III-R checklist of behavioural items). They found that this more systematic approach enhanced "reliability of measurement but at the expense of adequately describing the full range of phenomena." The authors highlighted the current confusion about the

[10] Secondary prevention of a psychiatric illness is possible when the following requirements are met: 1) knowledge of pathophysiological mechanisms; 2) availability of methods of early detection; and 3) means of intervention and correction of the pathophysiological changes (Adler, Levinson, & Astrachan, 1978).

[11] Primary prevention (i.e. preventing a psychiatric illness from happening) is achievable if the cause is understood and if it is feasible to avoid or manipulate the cause (or causes). Efforts at primary prevention have limited effectiveness when little is known about etiology (Adler *et al.*, 1978).

nature of prodromal features and concerns regarding the reliability of their measurement. They emphasized the need for more systematic evaluation of the prodromal phase in first-episode psychosis.

Yung and McGorry (1996-b) also used a retrospective approach to describe the prodromal symptoms in first-episode psychosis patients. Using a combination of unstructured and semi-structured methods, they interviewed first-episode patients (n=21) in the recovery phase after the first acute episode about the period leading up to the psychosis. The study found a wide variability of phenomena and sequence patterns, with symptoms being "a mixture of attenuated psychotic symptoms, neurotic and mood-related symptoms, and behavioural changes" (Yung & McGorry, 1996-b, p. 597). Yung and McGorry noted that "the symptoms were often disabling and some, such as suicidal thoughts, potentially life-threatening" (Yung & McGorry, 1996-b, p. 597). This study laid the groundwork for the development of better methodologies for assessing and measuring the psychotic prodrome with increased emphasis on experiential phenomena. The authors concluded that this has the potential to lead to the early detection and more accurate prediction of subsequent psychosis, as well as a deeper understanding of the neurobiology of the onset of psychotic illness.

A Norwegian group (Larsen, Friis, Haahr, Joa, Johannessen, Melle, Opjordsmoen, Simonsen, & Vaglum, 2001) reviewed the literature on early intervention in psychosis and evaluated the relevant studies with the intent of studying the prodromal phase and duration of untreated psychosis. In this review, early intervention was defined as primary prevention (intervention in the

prodromal phase) and secondary prevention (intervention after the onset of psychosis designed to shorten the duration of untreated psychosis). They reported that no studies were identified that "proved that intervention in the prodromal phase is possible without a high risk for treating false positives" (Larsen *et al.*, 2001, p. 324). They identified some studies aimed at reducing DUP, but they concluded that results were ambiguous and they did not find evidence showing a positive effect on prognosis. The team concluded that, based on current evidence, "reduction of DUP seems to be the most promising strategy" (Larsen *et al.*, 2001, p. 333). They cautioned that intervention in the prodromal phase is more ethically and conceptually troublesome.

A large McGorry-led team (2002) conducted a randomized controlled trial of interventions designed to reduce the risk of progression to first-episode psychosis. This trial compared two interventions in 59 patients at "incipient risk of progression to first-episode psychosis." They termed this group "ultra-high risk" to emphasize the enhanced risk versus conventional genetic high-risk studies. Needs-based intervention was compared with specific preventive intervention comprising low-dose risperidone therapy and cognitive behaviour therapy. Treatment was provided for six months, after which all patients were offered ongoing needs-based intervention. Assessments were performed at baseline, six months, and 12 months. Results showed that by the end of treatment, 10 of 28 people who received needs-based intervention progressed to first-episode psychosis versus three of 31 from the specific preventive intervention group. After six-month follow-up, another three people in the specific preventive intervention group became psychotic, and with intention-to-

treat analysis, the difference was no longer significant. However, for risperidone therapy–adherent patients in the specific preventive intervention group, protection against progression extended for six months after cessation of risperidone use. The authors stated that “more specific pharmacotherapy and psychotherapy reduces the risk of early transition to psychosis in young people at ultra-high risk, although their relative contributions could not be determined” (McGorry *et al.*, 2002, p. 926). They concluded that this represents at least a delay in onset (prevalence reduction), and possibly some reduction in incidence.

As this body of research matured, psychiatric researchers started to recognize that significant disability produced by psychotic illness develops during the prepsychotic period, creating a case for intervention during this period (McGorry *et al.*, 2002). However, only more recently have clinicians begun to engage people in treatment during this phase (McGorry *et al.*, 2002). As a result, psychosis prevention services started to develop. One such Canadian example, the Prevention through Risk Identification and Management (PRIME) Research clinic in Calgary targets younger people (beginning at age six) who are concerned with a recent change in their thoughts or feelings (J. Addington & Addington, 2001). Signs that someone may be at risk for greater difficulties include a decline in work or school performance; social withdrawal; trouble concentrating, focusing or thinking clearly; feeling suspicious or worried about the intentions of other people; and changes in the way things look or sound (J. Addington & Addington, 2001). These experiences may be accompanied by mood shifts such as depression, anxiety or outbursts. The PRIME Clinic offers a medication trial as well as individual and family therapy (focusing on education,

management and coping strategies), and community education (including media advisories, school outreach, etc). These and other advances in early intervention and psychosis prevention have come about as a result of ongoing evaluation initiative from around the globe.

2.7 Evaluation of early intervention in psychosis

The evaluation of early intervention in psychosis programs became a prime focus in the literature because these programs were new and the model's outcomes had not yet been measured. As well, there were unanswered questions about the model's costs. Consequently, Edwards and McGorry (2002) devote a chapter of their book, *Implementing Early Intervention in Psychosis: A Guide to Establishing Early Psychosis Services*, to program evaluation. They advocate for comprehensive evaluation that encompasses both quality control and outcome measurement. Chapter 7 of their book outlines the following five-phase method of evaluation based on Owen and Rogers (1999):

1) Describing the service model – documents from existing services can be used, with progressive refinement of draft documents.
2) A framework for program evaluation – what the program is designed to do and how it meets its goals.
3) "Clarificative evaluation" - consisting of three main elements: a) *program monitoring* (collection of data to evaluate how a program is doing, with reference to established targets and standards); b) *process evaluation* (examination of clinical procedures and activities);

and c) *outcome evaluation* (assessing outcome domain such as symptomatology and evaluation of treatment integrity i.e. the difference between what is "promised" and what is "delivered").

4) Integrating program description and evaluation – the use of existing clinical data to generate practice-based research.
5) Evaluation and quality officer – suggested responsibilities and duties of an evaluation and quality officer including development and delivery of evaluation and quality monitoring activities, support and assistance to staff regarding evaluation issues, assistance with research evaluation projects, coordination of data management, preparation of reports and briefing documents, development of research funding submissions.

Edwards and McGorry (2002) conclude that evaluation is critically important to satisfy senior management and funding agencies, influence other clinicians and policy makers, and ensure that finite resources are used efficiently and effectively.

2.7.1 Canada – early intervention evaluation

A number of Canadian sites have focused their attention on the evaluation of early psychosis intervention. This section discusses evaluation efforts in Calgary, Hamilton, London and Halifax.

Calgary

The Calgary Early Psychosis Program has undertaken a number of evaluation studies. Overall, they have studied the effectiveness of the program

on many dimensions of outcome including addictions, quality of life, family stress, symptoms and relapse. Results include:

- a reduction in substance use (J. Addington & Addington, 2001-b);
- significant improvement in quality of life (J. Addington, Young, & Addington, 2003);
- a reduction in family stress and burden (J. Addington, Jones, Ko, & Addington, 2000);
- improvement in positive symptoms by three months, depression increased at three months but significantly improved by twelve months, and negative symptoms changed little over the first year (J. Addington, Leriger, & Addington, 2003).

The Calgary evaluation efforts have excelled in the area of clinical outcomes with most of their published studies at the one-year mark. The program followed 300 people for up to three years, although about 40 percent were lost to follow-up (White, 2005). In particular, the Calgary work has advanced the area of family distress and family intervention. Nevertheless, the Calgary studies have not included control groups and they have not undertaken controlled trials. The Calgary Depression Scale, a product of this team, is commonly used in early intervention programs to measure depression in early psychosis (D. Addington, Addington, & Schissel, 1990).

Hamilton

Archie and team (2005) from the Psychotic Disorders Clinic (PDC) in Hamilton, Ontario studied the 12-month outcomes after treatment to determine

whether first-episode patients (n=40) achieved improved symptom control and functioning and fewer hospitalizations. Prospective longitudinal data were collected at baseline, three, six, and 12 months. Outcome measures included symptoms, global functioning, employment rates, duration of untreated psychosis, and number of bed-days. Results include:

- of the 40 patients, 37 completed the study at 6 months, and 31 at 12 months;
- significant improvements occurred in psychiatric symptoms, global functioning and the mean number of hospital bed-days;
- the mean BPRS scores were improved from a mean of 40 to a mean of 24 after 12 months of PDC treatment;
- the average Hamilton Depression Rating Scale decreased from thirteen to three at twelve months;
- the GAF scores improved from a mean of 44 to a mean of 71;
- the relapse rate (defined as a 20% increase in BPRS scores, compared with baseline) was 5% at both six and 12 months;
- scores on all measures were significantly improved at the 3-, 6-, and 12-month mark, compared with baseline - however, across all the measures, they discovered no significant difference between the scores at 6 and 12 months;
- the average number of days in hospital decreased from 23 days in the six months prior to PDC; it decreased to three days during the 12 months of PDC treatment.

The Hamilton team concluded that “it is feasible for small outpatient services to provide early intervention strategies and obtain good outcomes among first-episode patients” (Archie, Wilson, Woodward, Hobbs, Osborne, & McNiven, 2005, p. 49). Like many early intervention studies, the Archie et al study (2005) had a small sample size (n=40) and no control group. Loss to follow-up at 12 months was high: nine out of 40 patients (22.5%).

London

Several published accounts describe the one-year[12] evaluation of the Prevention and Early Intervention Program for Psychoses (PEPP) in London, Ontario (n=53). Patients were assessed at baseline and at one year with a modified version of the Interview for Retrospective Assessment of Onset of Schizophrenia, the Structured Clinical Assessment for DSM-IV, the Scale for Assessment of Positive Symptoms and the Scale for Assessment of Negative Symptoms. Results include:

- a complete remission rate of 70 percent (Malla *et al.*, 2002-b);
- a hospital readmission rate of 20 percent (Malla *et al.*, 2002-b);
- a highly significant improvement in all dimensions of psychopathology (Malla *et al.*, 2002-b);
- higher rates of remission among patients who entered treatment within six months of the onset of psychosis (eighty-two percent compared with sixty percent) (Malla *et al.*, 2002-b);
- a longer median duration of untreated psychosis among patients who did not experience complete remission (10.5 compared with 6.5 months) (Malla *et al.*, 2002-b);
- high rates of retention (81.5%) and remission (75%) (2003) (Malla, Norman, McLean, Scholten, & Townsend, 2003);
- significant improvements for self-reported Quality of Life (Malla *et al.*, 2003);

[12] Later work presents three-year outcomes (Norman *et al.*, 2005).

- improvements in cognition (Malla *et al.*, 2003);
- systemic changes to improve access to the service resulted in substantial increases in number of cases treated and a >50% decline in DUP (Malla *et al.*, 2003);
- improved social support and symptom control at three years (Norman *et al.*, 2005).

Malla et al. (2002-b) concluded that:

> An epidemiologically representative sample of patients experiencing a first episode of psychosis, when treated optimally with low dosages of novel antipsychotics and phase-specific psychological interventions, showed a high rate of clinical recovery and were able to remain in the community most of the time. A phase-specific intervention provided soon after the onset of a first episode of psychosis is likely to engender a more hopeful outlook. (p.461)

Halifax

Whitehorn and team (2002) used a multi-dimensional model to evaluate the outcomes of clients (n=103), not previously treated with antipsychotic medications, who enrolled in the Nova Scotia Early Psychosis Program and completed one year of treatment for schizophrenia or related psychotic disorder. The study team proposed operational criteria for defining recovery in five symptom dimensions and two functional dimensions including an overall functional dimension that they characterized as “return to the life line.” The clients were assessed with the Positive and Negative Syndrome Scale (PANSS), the Global Assessment of Function scale (GAF) and the Social and Occupational Functional Assessment scale (SOFA) prior to starting antipsychotic medication and again at six and twelve months of treatment. After

one year of treatment, 67 percent of clients met the study's criterion for symptomatic recovery (no relevant PANSS item greater than 'mild') for both positive and negative symptoms. Forty-two percent met the recovery criteria for all five symptom dimensions. The research team noted that most of the symptom improvement occurred during the first six months of treatment. At one year, 50 percent of clients met the study's criterion (SOFAS greater than 60) for overall functional recovery ("return to the life line"). The authors concluded that for clients completing the first year of treatment in the Nova Scotia Early Psychosis Program, approximately half achieved recovery in all dimensions.

Like other early intervention studies, the Nova Scotia group looked at one-year outcomes and did not use a control group. Their study criterion for overall functional recovery ("return to the life line") is a useful construct, but would benefit from a more multi-dimensional definition. The Halifax team found that most symptom improvement occurred during the first six months of treatment, a finding that corroborates the results of Archie et al. (2005) in Hamilton.

2.7.2 Australia – early intervention evaluation

Australia has been at the forefront of early intervention development and evaluation. One of the earliest published evaluations was undertaken by Patrick McGorry and colleagues (1993) in Melbourne of the Early Psychosis Prevention and Intervention Centre (EPPIC). The McGorry team compared outcomes of 51 EPPIC patients treated in 1993 with 51 pre-EPPIC historical controls (1989-1992) who were matched for key variables. The historical patients were treated

in the “standard” program, an intensive inpatient program established prior to the EPPIC program. After one year, the EPPIC clients had (with all differences statistically significant) a lower number of hospital admissions, shorter length of stay in hospital, lower levels of negative symptoms, lower mean dose of antipsychotic drugs and higher scores on a measure of quality of life. McGorry’s team concluded that a change in the *content* and the *timing* of initial treatment of psychosis lead to better outcome.

Yung and team (2003) evaluated the current practice at a generic adult mental health service, St Vincent's Mental Health Service (SVMHS), in Melbourne, Australia in relation to management of patients with early psychosis. Next, they compared treatment of early psychosis patients within this generic service with management of a similar group in a specialized early psychosis service (EPPIC). Using a standardized audit tool, they completed a case file audit of all patients identified as having early psychosis (within the first two years of treatment). They studied the following variables: 1) proportion of early psychosis admitted as inpatients to the psychiatric unit; 2) average length of stay (LOS); 3) use of seclusion; 4) involvement of police in admission process; 5) mean neuroleptic dose and 6) estimated duration of untreated psychosis (DUP). Results of this audit were then compared with published evaluative data from the Early Psychosis Prevention and Intervention Centre (EPPIC), a service specifically designed for young people with early psychosis (within the first 18 months of treatment). Data were collected on 62 of 68 patients identified as having early psychosis. Within the generic service, mean DUP was found to be about 15 months, a high proportion (81%) of patients were admitted and

secluded (22% of those admitted), average length of stay was 46.5 days and use of police in the admission process was also high (40% of those admitted). This compares unfavourably with the EPPIC data of mean DUP of just over 6 months, 64.1% of patients admitted, 10.3% secluded, average length of stay 12.9 days, and police involved in 3.8% of admissions. The team believed that practice at SVMHS in relation to early psychosis patients is fairly typical of management of these patients within generic services as a whole. These services tend to focus on the needs of the majority of their patients, those with chronic schizophrenia, rather than the small group of patients with early psychosis (who make up about 8% of current case-load at SVMHS). Failure to assertively assess and follow-up young people with early psychosis may contribute to long DUP, which may in turn result in patients being more disturbed at time of initial treatment, thus requiring inpatient treatment and longer length of stay. Additionally, staff at generic services may not feel confident in managing early psychosis patients and may be unaware of the special needs of this patient group. The team concluded that these preliminary findings suggest that "generic services are not optimal for treatment of early psychosis patients and that treatment of early psychosis within them is not cost-effective."

Nash and associates (2004) in Sydney, Australia examined whether staff training and service restructuring resulted in improved clinical outcomes for young people with first-episode psychosis. Staff attended workshops on the treatment of early psychosis for a four year period (1997 – 2000). Following service restructuring, specialized early psychosis teams began operating between 1998 and 2000. No additional funding was provided for clinical

services, but the restructuring resulted in a shift in resources. During this period a comprehensive assessment package including the Brief Psychiatric Rating Scale, Scale for the Assessment of Negative Symptoms and the Health of the Nation Outcome Scale was introduced. Using this assessment package, clinicians assessed patients at intake, three months and 12 months into treatment. Of 215 eligible first-episode patients, 94 consented to take part in the study. Symptom scores of patients treated earlier in the project were compared with those patients treated later, after more training and service developments had occurred. Regardless of the year of treatment, significant improvement in psychiatric symptoms was found over the three assessment periods. Individuals who entered the service in the latter phase of the project experienced fewer negative symptoms after 12 months of treatment compared with patients who entered the service in the early phase of the project. The authors concluded that improvements in both pharmacological and possibly psychosocial treatment may have led to a greater improvement in negative symptoms.

2.7.3 Sweden and Norway – early intervention evaluation

A research team led by Cullberg (2002) evaluated one-year outcome in first-episode psychosis patients in the Swedish Parachute project. This study used two comparison groups: one historical group (n=71) and one prospective group (n=64) from a “standard treatment” clinic. A total of 175 Parachute patients were followed through the first year of treatment. The team found that Global Assessment of Functioning (GAF) values were “significantly higher than in the historical comparison group but similar to the prospective group”

(Cullberg, Levander, Holmqvist, Mattsson, & Wieselgren, 2002, p. 282). They found lower levels of psychiatric in-patient care and prescription of neuroleptic medication, and they described satisfaction with care as “generally high” in the Parachute group. The team concluded that it “is possible to successfully treat first episode psychosis patients with fewer in-patient days and less neuroleptic medication than is usually recommended, when combined with intensive psychosocial treatment and support” (Cullberg *et al.*, 2002, p. 284).

A Danish research team led by Lone Petersen (2005), as part of the OPUS trial, evaluated whether integrated treatment compared with standard treatment reduced the proportion of patients with poor clinical and social outcome after one year. A total of 547 patients with first-episode psychosis were included in the study, 275 randomly assigned to integrated treatment and 272 to standard treatment. Measures assessed psychotic symptoms and social functioning. There was a significant beneficial effect of integrated treatment versus standard treatment on “poor outcome.” Integrated treatment had a significantly better effect on “poor outcome” in patients with schizophrenia compared with patients in standard treatment. The team concluded that “the integrated treatment significantly reduced the proportion of patients with poor clinical and social outcome compared with standard treatment” (Petersen, Nornentoft, Jeppensen, Ohlenschlaeger, Thorup, Christensen, Krarup, Dahlstrom, Haastrup, & Jorgensen, 2005, p. 102). This study and its randomized experimental design represent one of the strongest and most compelling pieces of evidence in support of the early intervention approach.

2.7.4 United Kingdom – early intervention evaluation

In the United Kingdom, one early intervention evaluation focused on an occupational therapy initiative that targeted young people (aged 16 - 25) who were experiencing or who had recently experienced psychosis (Fisher & Savin-Baden, 2001). The program, known as “TIME”, provided evidence-based psychosocial therapies, specifically early intervention, family intervention, cognitive therapy and cognitive-behavioural therapy, and occupational therapy. The program was evaluated by gaining the perspectives of the key stakeholders, both consumers and providers of the program. Although TIME was valued by the service users, the findings indicated discrepancies between the “embedded values and norms of the health care systems and those espoused by theorists” (Fisher & Savin-Baden, 2001, p. 64).

Craig and colleagues (2004) evaluated the effectiveness of an early psychosis service in greater London, United Kingdom using a randomized controlled clinical trial design. Study participants included 144 people (ages 16 - 40) presenting to mental health services with non-organic, non-affective psychosis. The study compared two interventions: assertive outreach with bio-psychosocial interventions and standard care. The primary outcome measures were rates of relapse and readmission to hospital. When rates were adjusted for sex, previous psychotic episode, and ethnicity, only total number of readmissions to hospital and dropout rates (i.e. maintaining better contact with service) were significant.

2.7.5 Common limitations of early intervention evaluation studies

Despite the limitations of these and other studies (small sample size in some instances, loss to follow-up, few studies with randomized controlled design), an emerging consensus supports the conclusion that early intervention programs achieve better clinical and social outcomes compared to standard treatment methods (Penn, Waldheter, Perkins, Mueser, & Lieberman, 2005). These outcomes are achieved at a lower cost per patient, primarily due to a reduction in in-patient care. Most studies present outcomes at one year or less, so there is continued need for longer outcome evaluation (two years and beyond). Other than cost, most studies do not focus on administrative matters but rather emphasize clinical outcome. Thus, the current findings in this area point to two important future directions (Penn *et al.*, 2005):

> 1) a greater number of randomized, controlled designs to provide a more stringent test of the efficacy of multielement programs and 2) utilization of research designs that will allow one to deconstruct the key ingredients of these programs and to determine the specific types of patients for whom these services are particularly beneficial. Single-element studies can be quite helpful in this regard. (p. 2230)

The recent Cochrane collaboration review of early psychosis care (Marshall & Rathbone, 2006) found insufficient data to draw definitive conclusions. This review identified seven trails (n=941) that involved people with prodromal symptoms or first-episode psychosis. Six studies were small with numbers of participants ranging between 56 and 83, and one study randomized 547 people. They noted that most of these studies were underpowered. The evidence base

surrounding early intervention in psychosis is evolving and expanding, and further trials are expected (Marshall & Rathbone, 2006).

3.0 EVALUABILITY ASSESSMENT

To lay the groundwork for the overall research study, an Evaluability Assessment of the SHR Early Intervention in Psychosis program was completed in 2000. The Evaluability Assessment methodology used was adopted from Rutman (1980) and Wholey (1987, 1994). According to Wholey (1987, p. 77), Evaluability Assessment is "a diagnostic and prescriptive technique that can be used to determine the extent to which different problems inhibit program evaluation." It involves managers and staff in developing program theory, clarifying intended uses of evaluation information, and planning further evaluations that would improve program performance. The Evaluability Assessment would assist in identifying and clarifying the program components and goals/effects of the Early Intervention in Psychosis program, and it would act as the foundation for development of the Program Logic Model. The Program Logic Model, in turn, would be used as the operational framework for the subsequent study.

3.1 Evaluability assessment methodology

3.1.1 Evaluability assessment

The first step of the Evaluability Assessment consisted of the review, analysis and interpretation of all available formal documents pertaining to the

Early Intervention Program's development, current structure, stated program objectives, goals and effects. This documentation included proposals, brochures, manuals, working papers, committee minutes, reports, and other relevant material. A list of the documents reviewed is included as *Appendix A*. This phase of the project was completed from December 1999 to February 2000.

The second step of the assessment was to develop a *Program Documents Model*, based on the review of the program documents. This step involved documenting the program's structure in a descriptive flow model, thereby identifying the program's components (activities) and goals/effects (immediate, intermediate and ultimate). The *Program Documents Model* for the Early Intervention Program is attached as *Appendix B*. This phase of the project was completed in February 2000.

The third step was to conduct semi-structured interviews to review and analyze the *Program Documents Model* and to determine how key stakeholders' perceptions of the program differed from the initial program model. This required the development of an Interview Schedule (*Appendix C*) with questions designed to clarify the program's activities and components, vague or conflicting goals/effects, and any apparent gaps in the causal linkages between the program's components and goals. Definitions used in the interview are attached as *Appendix D* and Choice Sheet options are attached as *Appendix E.* Next, program stakeholders were identified and interviewed to obtain their view of the *Program Documents Model*. A total of nine interviews were conducted with the Program's two consultant psychiatrists, two registered psychiatric nurses, one

program manager, two clients and two family members (*Appendix F* - Interview Timetable). Each psychiatric nurse recommended one client and family member to be interviewed. It was determined that clients and families could appropriately address all areas of the *Program Documents Model*, therefore the same Interview Schedule was used for both staff and clients/family. Prior to interviews being conducted, participants provided written consent.

The fourth step of the assessment was to develop nine different *Program Manager's Models*, based on information obtained from the stakeholders' interviews (see *Appendices G-1* through *G-9*). The accuracy of the stakeholders' models was verified by providing them with a color-coded copy of their respective model, with feedback provided via telephone and/or face-to-face meeting. This allowed stakeholders the opportunity to confirm that their model correctly reflected their view of the program. Eight of the nine stakeholders were satisfied their model accurately reflected their viewpoint, and this was verified by a short telephone conversation. This high level of accuracy is attributed to three factors: 1. the interview questionnaire was comprehensive and detailed; 2. the original *Program Documents Model* was color-coded for clarity and ease of review; and 3. the interviewer and interviewees sat in close proximity (side-by-side) during the interviews. During the feedback stage, one stakeholder requested a brief follow-up meeting in addition to the telephone call. At this meeting, specific terminology was clarified and expanded. Specifically, the term “crisis service” was added to his/her model. Comparison of the nine different models was then used to facilitate judgments about various evaluation options.

The fifth step was to develop an *Evaluable Program Model* (*Appendix H*), derived from the comparisons of the flow models and the field data. This step involved the identification of which program components and goals/effects should be considered for inclusion in the evaluation study. This involved an integration process by which several sources of information were considered. Preconditions to evaluation: 1) program components are well defined and can be implemented in the prescribed manner; 2) goals and effects are clearly stated and agreed-upon; 3) causal linkages are plausible. Those aspects of the program that according to the evaluator met the preconditions were depicted in boxes with solid lines. Those aspects that did not meet the preconditions were depicted in boxes with broken lines.

The sixth step of the assessment was to discuss options for evaluation suggested by the *Evaluable Program Model* with program stakeholders (i.e. Program staff and manager) who would then sponsor and support the actual evaluation. These options took into consideration feasibility in terms of resources and priorities of the Program, taking into account the *Evaluable Program Model*.

The seventh step of the assessment was to suggest preliminary measures and instruments that could be utilized in the formal evaluation. This stage included clarifying the nature of the actual evaluation to be done, based upon the results of the Evaluability Assessment, the priorities of the agency, and the feasibility of the project.

The eighth step was to prepare and discuss the final report with the Early Intervention Program team in order to determine the value of the final report in

the planning of the future evaluation of the Early Intervention Program. A confidential final report describing the evaluability assessment and its recommendations was provided to the Agency Supervisor. Clients and families also received a report summary, with a cover letter thanking them for their assistance.

The final step of the assessment was to facilitate a program development meeting with the Early Intervention Program Committee, at which time the Committee clearly identified and defined the program's goals/effects and program components (in areas where conflicting views and vague goals were identified). This meeting, which represented an important opportunity for knowledge transfer, was held with the Early Intervention Program Committee on June 20, 2000.

3.1.2 Interview schedule

In order to clarify the program components and goals/effects of the Early Intervention Program, an Interview Schedule (*Appendix C*) was constructed (adopted from Clark & Grant, 1998). Because the program is small, it was decided to interview all staff directly related to the program, namely the program's two consultant psychiatrists and two program psychiatric nurses. Each of these highly experienced individuals was considered instrumental to the program's development and ongoing operation. Both psychiatrists are professors in the Department of Psychiatry, College of Medicine and bring considerable expertise in clinical work, administration and research. The psychiatric nurses each bring more than twenty years experience in acute and

community-based mental health nursing. The program's manager, an occupational therapist and health administrator by training, was interviewed to gain his perspective based on his line management responsibility and budget accountability for the program. To obtain the consumer's perspective, two clients and two family members were interviewed. Interviews were conducted in a session lasting about one hour and fifteen minutes.

The *Program Documents Model (Appendix B)* was color-coded to assist the interviewees in focusing on the applicable areas of the model as the interview was being conducted. The first series of questions focused on the program components, in an effort to ascertain whether or not the respondent viewed the component as part of the Early Intervention Program. If the component was deemed to be part of the program, the respondent was then asked to clarify the meaning of the component, and to comment if he/she believed the component was appropriately labeled. The second part of the interview focused on the immediate, intermediate and ultimate goals/effects of the program. Again, the respondent was invited to clarify the meaning of the goal/effect and to suggest what types of evidence would convince him/her that the goal/effect had been achieved. Summary questions helped clarify if any components or goals/effects were missing from the Program Documents Model or if unintentional effects and conflicting goals existed. In closing, the respondent was invited to discuss the links between program components and goals/effects.

3.2 Evaluability assessment results

3.2.1 Program documents model

Program Components: The Program Documents Model (*Appendix B*) identified four main components (color-coded in blue): 1) Diagnosis and Assessment; 2) Psychiatric Consultation; 3) Psychoeducational Interventions; and 4) Psychosocial Interventions. The program components of Psychoeducational Interventions are Early Information Sessions, Individual Information Sessions and Group Education Sessions. The program components of Psychosocial Interventions are Stress Management Training, Goal Planning Training, Coping Skills Training, and Therapy. Medication Management Training is a program component related to Psychiatric Consultation. Assessment and Diagnosis and Psychiatric Consultation are over-arching program components which impact the other program components.

Program Goals/Effects: The documents identified fourteen immediate goals (color-coded in green). The first goal is to increase the individual and family's knowledge and understanding of their illness, which fosters the second goal of reducing misconceptions about psychotic disorders. The third and fourth goals are to promote early commitment to the program and to establish a therapeutic relationship with the client, which promote the fifth goal of increasing compliance to treatment. The sixth goal is to create a supportive environment of people and families with the same illness. The seventh goal is to improve the ability of clients and families to manage stress. The eighth goal is to increase the individual's ability to goal plan. The ninth goal is to improve the client and

family's ability to cope with the illness. The tenth goal is to improve the client's life skills. The eleventh goal is to increase the client's self-confidence and self-esteem. The twelfth goal is to manage co-existing symptoms such as anger and depression. The thirteenth goal is to improve the individual's ability to manage medications, which promotes the fourteenth goal of reducing the primary symptoms of psychosis.

There are three intermediate goals (color-coded in pink) identified by the documents review. The first intermediate goal is to reduce the possibility and severity of relapse. The second intermediate goal is to reduce the burden and stress on self and family. The third intermediate goal is to decrease the use of emergency and crisis services.

The documents identified three ultimate goals of the program (color-coded in red). The first ultimate goal is to optimize quality of life (of the individual and their family). The second ultimate goal is to increase future employability. The third, and final, ultimate goal is to reduce utilization of health services.

3.2.2 Program managers' models

Semi-structured interviews were conducted with nine stakeholders to explore their perceptions of the Early Intervention Program. Convergence of the various perspectives provided some confidence that the Program Documents Model accurately represented most aspects of the Program. The interviews also identified a number of discrepancies between the stakeholders'

models and the Program Documents Model. Differences amongst the stakeholders' models were also identified.

All stakeholders confirmed Diagnosis and Assessment and Psychiatric Consultation as components of the program. One consultant psychiatrist re-labeled the second component *Psychiatric Consultation to Program Team*, to differentiate this activity from a standard "psychiatric consult." Likewise, all stakeholders confirmed Psychoeducational Interventions and Psychosocial Interventions as main program components. All but one stakeholder confirmed Medication Management Training and Medication Monitoring as a program component. All stakeholders identified Early Information Sessions, Individual Education Sessions and Group Education Sessions as components of the program. Under the category, Psychoeducational Interventions, one program nurse added *Drug & Alcohol Awareness and Education* and the program's manager added *Community Education Sessions (Schools, etc.)*.

More significant discrepancies were found under the fourth category, Psychosocial Interventions. The **first major discrepancy**, found between the Program Documents Model and the stakeholders' perceptions, involved the component Stress Management. One program psychiatrist omitted this component, one program nurse felt it applied only to clients, and the program manager amalgamated it with another component (Goal Planning Training). All stakeholders but one (the program manager) confirmed Goal Planning Training as a component of the program, while one consultant psychiatrist added "includes Problem Solving" to the label. All stakeholders confirmed Coping

Skills Training as a component of the program, with the program manager amalgamating it with Stress Management Training.

The **second major discrepancy**, between the Program Documents Model and the stakeholders' models, involved the program component, Life Skills Training. One consultant psychiatrist and one program nurse re-named this component *Referral to Life Skills Training*, believing this to be an external resource available to clients but not offered directly by the program. The second consultant psychiatrist omitted Life Skills Training from his model, referencing the availability of other community resources. The second program nurse and the program's manager included Life Skills Training in their models, but defined it with respect to daily living skills (such as waking up on time, being punctual, etc.) rather than occupational life skills. The two clients and two family members all included Life Skills Training in their models.

The **third major discrepancy** involved the program component, Therapy: Individual and Family. One program nurse and one family member included this component in their models, while four stakeholders (one consultant psychiatrist, the program manager, one client and one family member) omitted this component from their models. One program nurse re-labeled this component *Referral to Therapy* and one consultant psychiatrist added "Referral If More Intensive" to the label. In addition, one client added "Intervention/Conflict Resolution" to the label.

All nine stakeholders confirmed Increase Knowledge and Understanding of Illness as an immediate goal/effect of the program, with one consultant psychiatrist adding "And Overcoming Denial of Illness" to the label. The **fourth**

major discrepancy involved the immediate goal/effect, Reduce Misconceptions About Illness. Five stakeholders (one consultant psychiatrist, both program nurses, one client and one family member) re-classified this goal/effect from the immediate to intermediate category. The remaining five stakeholders confirmed it as an immediate goal/effect. Eight stakeholders confirmed Promote Early Commitment to Program and Establish Therapeutic Relationship with Client/Family as immediate goals of the program. The immediate goal Increase Compliance to Treatment was confirmed by eight stakeholders, re-classified as intermediate by one program nurse, and not included by one family member. The **fifth major discrepancy** between the Program Documents Model and the stakeholders' perspectives involved the immediate goal, Create a Supportive Environment of People/Families with the Same Illness. This goal/effect was confirmed by four stakeholders (one consultant psychiatrist, the program manager, and both clients), not included by one consultant psychiatrist, and re-classified as an intermediate goal by both program nurses and both family members. Both program nurses and one family member showed this goal/effect as linking to the intermediate goal/effect, Reduce the Possibility and Severity of Relapse.

The **sixth major discrepancy** involved the immediate goal/effect, Improve Ability to Manage Stress. One consultant psychiatrist, two clients and two family members confirmed this goal/effect as presented in the Program Documents Model. The other consultant psychiatrist omitted this goal/effect from his model. Both program nurses and the program's manager re-labeled this goal/effect *Increase Knowledge of Stressors and Responses*, and re-

classified the original goal/effect, Improve Ability to Manage Stress, as an intermediate goal. The **seventh major discrepancy** involved the immediate goal/effect, Improve Ability to Goal Plan. One consultant psychiatrist and both clients confirmed this goal as presented in the Program Documents Model, while the other psychiatrist added "And Problem Solving" to the label. Both program nurses re-labeled this goal/effect *Increase Knowledge of Goal Planning Techniques*. The two program nurses and both family members re-classified the original goal, Improve Ability to Goal Plan, as an intermediate goal/effect. Five of the nine stakeholders confirmed the immediate goal/effect, Improve Ability to Cope with Illness. The two program nurses re-labeled this immediate goal, Increase Knowledge of Coping Skills Techniques, and re-classified the original goal/effect (Improve Ability to Goal Plan) as an intermediate goal/effect. The **eighth major discrepancy** involved the immediate goal/effect, Improve Life Skills. One consultant psychiatrist and two family members confirmed this goal as presented in the Program Documents Model. The other psychiatrist and one program nurse did not include this goal in their models. The remaining four stakeholders (one nurse, the manager and both clients) re-classified this goal as an intermediate goal/effect (with no immediate goal/effect preceding it). The **ninth major discrepancy** involved the immediate goal, Increase Self-Confidence and Self-Esteem. One psychiatrist, one client and one family member confirmed this goal/effect as presented in the Program Documents Model. The other psychiatrist re-classified this goal/effect as an ultimate goal/effect, while both program nurses re-classified it as an intermediate goal/effect. One client and one family member did not include this goal/effect in

their models. The **tenth major discrepancy** involved the immediate goal/effect, Manage Co-existing Symptoms (Anger, Depression). Three stakeholders (one psychiatrist, one client and one family member) included this goal/effect in their models as originally presented. The program manager and one client omitted this goal/effect from their models. The remaining four stakeholders (one psychiatrist, both nurses, and one family member) re-classified this goal/effect as intermediate, rather than immediate. The immediate goal, Improve Individual's Ability to Manage Medication, received only minor modifications. One client omitted this goal/effect from his/her model, and both program nurses re-classified this goal/effect from immediate to intermediate. The final immediate goal/effect, Reduce Primary Symptoms of Psychosis (Duration and Severity), received a full endorsement from all nine stakeholders, highlighting their common sense of purpose in this regard.

The intermediate and ultimate goals/effects received only minor modifications. The intermediate goal/effect, Reduce the Possibility and Severity of Relapse, was confirmed by seven program stakeholders. One program nurse and one client re-classified this goal/effect from intermediate to ultimate. Likewise, the intermediate goal/effect, Reduce the Burden of Stress on Self and Family, was confirmed by seven program stakeholders, and was re-classified as an intermediate goal/effect by one client and as an ultimate goal/effect by one family member. The intermediate goal/effect, Decrease Use of Emergency/Crisis Services, was re-labeled in two instances: one consultant psychiatrist added "and Acute" to the label and the program's manager re-named this goal/effect, *Facilitate Appropriate Use of Health Services*. One

family member omitted this goal/effect from his/her model. The ultimate goal/effect, Optimize Quality of Life for Individual and Family, was confirmed by all stakeholders. Six stakeholders included the ultimate goal/effect, Increase Future Employability, in their models, while the program's manager omitted this goal/effect. One consultant nurse re-named this goal/effect, *Maximize Individual's Ability to Be Employable*. One family member re-named this goal/effect, *Facilitate Future Employability*. The last ultimate goal/effect, Reduce Utilization of Health Services, was confirmed by six stakeholders and omitted by one (the program's manager). One family member changed the word "health" to "hospital," commenting that community-based programs would always be required. One consultant psychiatrist added "Illness Related" to the label, noting that the program cannot attempt to decrease utilization of services not related to the client's mental illness (e.g. cancer, diabetes, heart conditions, etc.).

3.2.3 Evaluable program model

The Evaluable Program Model (*Appendix H*) was developed based on the review of the documents, interviews with nine program stakeholders, review of field data (client profiles), and a brief review of the literature. The model identifies the program components and goals/effects that are currently realistic and measurable. The Evaluable Model most closely resembles the combined models of the program nurses because it was believed that they had the best "working knowledge" of the program. Most notably, Life Skills Training and Therapy are not included in this model because it appears these activities are external to the Early Intervention Program. Thus, the appropriate referral

mechanisms need to be clarified. The immediate goals of Psychosocial Intervention were modified to reflect knowledge components, while the intermediate goals were re-structured to focus on "improve ability." The goals Reduce Misconceptions about Psychotic Disorders and Create a Supportive Environment of People/Families with Same Illness were re-classified as intermediate goals. Other areas remained essentially intact.

Preconditions to evaluation include: 1) program components are well defined and can be implemented in the prescribed manner; 2) goals and effects are clearly stated and agreed-upon; 3) causal linkages are plausible. Those aspects of the program that according to the evaluator met the preconditions were depicted in boxes with solid lines. Those aspects that did not meet the preconditions were depicted in boxes with broken lines.

3.3 Program theory - development of a program logic model

The relevance of program theory to evaluation has been recognized for some time (Lipsey & Cordray, 2000; Weiss, 1972). Most common is the use of theory as a planning tool for an evaluation (Julian *et al*.,1995). This includes the program logic models derived during an evaluability assessment (Wholey, 1994). Their purpose is to determine whether “an agreed-upon conceptualization of the program exists, what it is, and whether it is sensible and feasible” (Lipsey & Cordray, 2000, p. 343). Program logic models typically show the key program activities, the program personnel and inputs involved, and the expected results (Cooksy, Gill, & Kelly, 2001; Lipsey & Cordray, 2000). Once laid out, they often lead to program reconceptualization or refinement, as well as serving to identify

questions that might be asked and variables that might be measured in an evaluation (Lipsey & Cordray, 2000).

Lipsey and Cordray summarize (2000, p. 346): "This form of program theory gives the evaluator a road map that directs attention to what stakeholders view as the critical program activities, the intended outcomes, and the presumed relationships between those activities and the intended outcomes." The SHR Early Intervention in Psychosis Program Logic Model, derived from the Evaluability Assessment, is presented in *Appendix I*. This creates the operational framework for the multi-method evaluation that follows (Cooksy *et al.*, 2001).

4.0 METHODOLOGY

4.1 Interdisciplinary perspective

An interdisciplinary perspective involves studying a subject using multiple viewpoints and methods, while cutting across disciplines. In particular, this study blends health administration and program evaluation with special consideration to three clinical disciplines (nursing, psychiatry and psychology). From the field of health administration, this study employs a model for assessing health quality: structure, process and outcome (Donabedian, 1966). This model acts as the over-arching conceptual framework for this study, and serves as the basis for the three study questions (presented in Chapter 1, Section 5). From the field of program evaluation, this study employs a program logic model which acts as the operational framework for this study (Rutman, 1980; Wholey, 1987). The program logic model (presented in *Appendix I*) identifies and clarifies the Early Intervention in Psychosis program's inputs, program components and immediate, intermediate and ultimate goals/effects. Using this interdisciplinary approach, a quality management "overlay" is used to address a program evaluation question. Table 4.1 cross-references the relationship between these two complementary frameworks.

Table 4.1 Cross-reference: health quality and program logic frameworks			
Program Logic Model Elements	Quality Domain		
	Structure	Process	Outcome
Inputs: Nursing Travel Other expenses			
Program components: Diagnosis/assessment Psychiatric consultation Psychoeducational interventions Psychosocial interventions Medication management			
Goals/effects: Immediate Intermediate Ultimate			

4.2 Conceptual framework

Donabedian (1966) proposed a model for assessing health care quality. He identified three dimensions of the quality of care: 1) **structure** – characteristics of service delivery (the environment in which health care is provided); 2) **process** – activities that occur between practitioner and patients (the method by which health care is provided); and 3) **outcome** – changes in the patient's current or future health (the consequence of the health care provided). These three dimensions of quality form the basis of the over-arching conceptual framework for this study (Fig. 4.1).

Figure 4.1 Early intervention in psychosis study: conceptual framework.

Note: Intellectual, physical, and spiritual outcomes were not assessed in this study.

4.3 Study schematic

The following schematic (Fig. 4.2) pictorially describes the design and methods used to study the structure, process and outcome of early psychosis services in the Saskatoon Health Region.

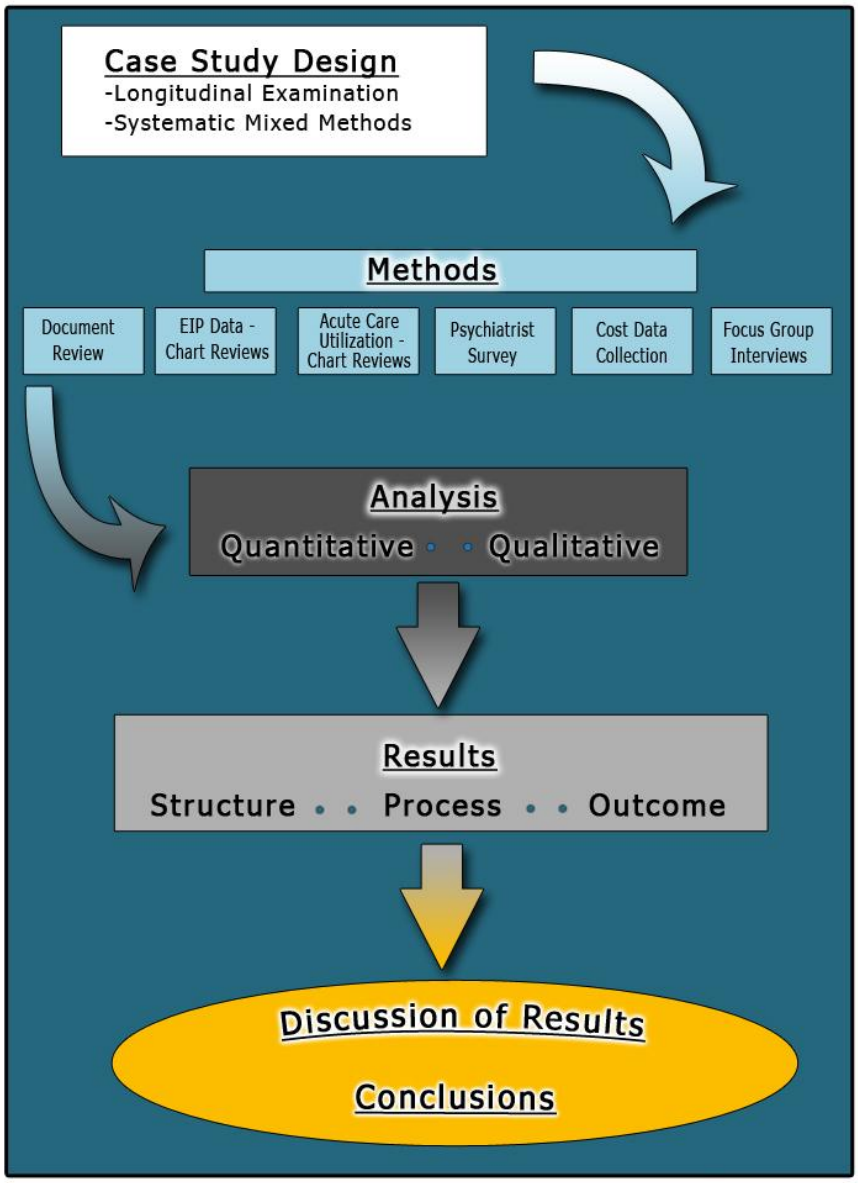

Figure 4.2 Early intervention in psychosis: study schematic.

4.4 Study design

The study was launched in May 1999, with ethics approval from the Saskatoon Health Region and the University of Saskatchewan (Ethics Certificate

No. Bio 99-60). After a number of design iterations, a case study design was selected.

Case study evaluation has gained recognition as a systematic way of collecting data, analyzing the information, and reporting results. The US Government Accounting Office (1990) defines case study evaluation as "a method for learning about a complex instance, based on a comprehensive understanding of that instance obtained by extensive description and analysis of that instance taken as a whole and in its context." The unit of study in a case study can range from an individual to a program to an organization. In this case, the unit of study is early psychosis care in the Saskatoon Health Region.

In recent years, case study research has gained popularity in a wide range of disciplines including education, management, planning, psychology, social work, and sociology (Yin, 2002). The case study approach helps researchers retain the holistic and meaningful characteristics of real-life events (Yin, 2002). For case studies, four components of a research design are particularly important (Yin, 2002):

1) the study's questions – well-defined study questions are needed to define the focus and scope of the case study.

2) the study's unit of analysis – the unit of analysis must be clearly defined and can range from an individual to a program to an organization or larger.

3) the logic linking the data to the study's purpose – in many cases a program logic model is used to link the program's goals/objectives to the respective study data.

4) the criteria for interpreting the findings – criteria need to be presented within the context of specific perspectives and biases.

Posavac and Carey (1997) identified a number of key advantages of the case study approach. First, case study design supports a longitudinal examination (Posavac & Carey, 1997), an important element of this study. This case study examines the evolution of early psychosis care in the Saskatoon Health Region over a 15 year period (1991-2006). It describes and compares two eras of care – the previous traditional approach (1991-1998) and the new early intervention approach (1999-2006). Clients studied from 1991-1998 are referred to as the *historical group* and clients studied from 1999-2006 are referred to as the *Early Intervention in Psychosis (EIP) group*. Second, the case study design is highly flexible, and provides a broad perspective of the unit being analyzed (Posavac & Carey, 1997). The case study approach is particularly applicable to program evaluation given that "programs rarely consist of a single treatment procedure but rather consist of an array of treatment procedures" (Feldman, 1979). It supports the use of multiple data sources, ensuring that a "full picture" is obtained (Posavac & Carey, 1997). When analyzing early psychosis care, it is important to take into consideration the overall health service environment and context. The case study allows the researcher to learn about the structure, process and outcome of early intervention services through extensive description and contextual analysis. It does not, however, allow statements about causation (Posavac & Carey, 1997). Feldman (1979) concurred that a program is a "complex bundle of procedures" that defies the determination of simple cause and effect relationships.

4.5 Study methods and data collection

This case study was undertaken using a mixed methods approach. Mixed methods research is defined as “a procedure for collecting, analyzing, and mixing both quantitative and qualitative data in a single study or series of studies” (Creswell & Plano-Clark, 2006, p.7). It is becoming more common in the social, behavioural and health sciences as well as education (Shih, 1998). Its central premise is that the use of quantitative and qualitative methods in combination provides a better understanding of research problems than either approach alone (Creswell & Plano-Clark, 2006, p.7).

While bearing some similarities, triangulation was not the objective of this study. Triangulation involves combining three or more methods to study the same construct or phenomenon (Yin, 2002). It can be used in quantitative, qualitative or mixed method studies. It is used to corroborate findings and to establish the accuracy of information by comparing three or more types of perspectives on independent data sources (e.g. interviews, survey, and documentation) (Yin, 2002). Triangulation can be viewed as an alternative to the traditional criteria of validity and reliability (Yin, 2002). Triangulation is commonly used in case studies. However, triangulation presents a number of analytical challenges including those outlined by Mitchell (1986): 1) How can quantitative (numerical) and qualitative (linguistic) data be combined? 2) How can divergent results between numerical and linguistic data be interpreted? 3) What can be done with overlapping concepts that emerge from the data? 4) Should data sources be weighted? 5) Should each method used be considered

equally valid and thus weighted equally? Consequently, this study does not formally employ a triangulation approach but rather uses a variety of quantitative and qualitative methods in a complementary fashion. The various data sources are cross-referenced to the Program Logic Model (*Appendix J*).

4.5.1 Identification of study clients: early intervention and historical

When the Saskatoon Health Region's new Early Intervention in Psychosis (EIP) program was launched, it was anticipated that the client numbers would be small. With a Saskatoon district population of approximately 300,000, the program would expect to admit about 30 new clients per year. This is based on an annual incidence rate for psychosis of one per 10,000 (Health Canada, 2002). To be eligible for the EIP program, clients needed to be diagnosed within two years prior to admission to the program. In the first two years of the program, 43 clients were admitted. Of the eligible clients, 29 of these clients consented to be part of the study. To increase the number of consenters, clients were offered the opportunity to participate in the two-year study at baseline (n=22) and two years (n=7). Clients were informed that participation or non-participation in the study would not affect the EIP services they would receive.

The historical group was identified from four sources (Table 4.2): 1) Saskatoon Health Region Child and Youth Services; 2) Saskatoon Health Region Mental Health Rehabilitation Services; 3) Local psychiatrists; and 4) Saskatoon Health Region Early Intervention in Psychosis Program (not "first break" at admission to program). It is important to note that while the sources used to identify the historical clients varied, their decentralized care was similar

and consisted of medical care (family medicine and psychiatry), in addition to out- patient services such as McKerracher Centre and Mental Health Rehabilitation Services. This resulted in an early intervention group of 29 clients and an historical group of 14 clients.

Table 4.2 Sources of clients for the historical group.

Source	Number of Files	Number of Files Meeting Criteria
Children & Youth Services	14	2
Rehabilitation	110+	10
Psychiatrists	5	4
EIP Program	1	1
Total	**130+**	**17* (14)**

Criteria:
- First break psychosis (1991-1998)
- Diagnosis – schizophrenia, schizoaffective disorder, psychosis NOS, etc.

** Three excluded following review (not "first break").*

It is recognized that a number of changes in the delivery of early psychosis care took place between the first era of care (1991-1998: represented by the historical group) and the second era of care (1999-2006: represented by the EIP group). First, increased bed utilization management impacted the length of stay of all hospitalized patients, including psychiatric patients. Second, the use of novel (atypical) antipsychotic medications became more wide-spread

during the second era of care. The potentially confounding effect of these variables must be considered when interpreting the findings of this study.

4.5.2 Assessment of early intervention in psychosis clients

Prospective longitudinal clinical data for the EIP cohort were collected by the two EIP psychiatric nurses, both with training and experience in the application of the study instruments. In 2002-03, they were assisted by the program's part-time research assistant, a doctoral student in clinical psychology. Baseline client data were obtained upon admission to the EIP program and at four follow-up points at six month intervals (6-months, 12-months, 18-months, 24-months). Demographic and socioeconomic characteristics were also collected. Prior to the inception of the Early Intervention in Psychosis program in 1999, these clinical instruments were not used on a consistent basis and, if used, were not recorded centrally. Consequently, this information was not available for the historical clients. The following instruments[13] were used to assess the EIP clients:

1. Structured Clinical Interview for DSM-IV (SCID-I)

The Structured Clinical Interview for DSM-IV Axis I Disorders (First, Spitzer, Gibbon, & Williams, 1996; Spitzer, Williams, Gibbon, & First, 1992) is a semi-structured interview for making the major DSM-IV Axis I diagnosis. Common Axis I disorders include depression, bipolar disorder and schizophrenia. The SCID is designed to be administered by a clinician or

[13] Initially, the EIP program intended to use the Family Concern Questionnaire (FCQ) to assess family caregiver burden. The FCQ is a 46-question self-report scale (Schene, 1990), Early in its operation, the EIP offered family group sessions but overtime this lapsed as a result of workload pressures. As a result, the FCQ was not consistently used across the two-year study period.

trained mental health professional, preferably someone who has had experience performing unstructured diagnostic evaluations.

2. Positive and Negative Syndrome Scale (PANSS)

The Positive and Negative Syndrome Scale (PANSS) is designed to measure the severity of psychopathology in adults with schizophrenia, schizoaffective disorder and other psychotic disorders (Kay, Fiszbein, & Opler, 1987). The PANSS includes three scales and thirty items. Seven items make up the positive scale which includes delusions, conceptual disorganization and hallucinatory behaviour. Seven items make up the negative scale that includes blunted affect, emotional withdrawal, poor rapport, passive/antisocial withdrawal, difficulty in abstract thinking, lack of spontaneity, and stereotyped thinking. Sixteen items make up the general psychopatholgy scale including anxiety, guilt feelings, depression, uncooperativeness, disorientation and poor attention, among others. The time period for the PANSS is normally the one week preceding the interview. Items are scored on an anchored Likert scale with values ranging from one to seven. Scores above one indicate that a clinical symptom is present. Detailed “anchors” are provided for each severity rating. Normative PANSS data is available from a study of 240 adult patients with DSM-III criteria for schizophrenia who were taking antipsychotic medication (Kay & Sevy, 1990). In this study, the 50^{th} percentile corresponded to a raw score of 20 on the Positive Scale and a raw score of 22 on the Negative Scale. Likewise, the 50^{th} percentile corresponded to a raw score of 40 on the General Pathology Scale.

3. Drug Attitude Inventory (DAI)

The Drug Attitude Inventory (Hogan, Awad, & Eastwood, 1983) assesses the client's subjective response to medications. The instrument, which consists of ten self-report items, focuses on unpleasant and negative adverse effects that are common with antipsychotic medications. Three items ask the clients to rate how the medications makes them feel (e.g. "like a zombie," "more relaxed," and "tired and sluggish"). Other items reflect attitudes and beliefs about medication effects. The nondysphoric response to six items is true and to four items is false. Nondysphoric responses receive a score of 1 and dysphoric responses are given a score of -1. The DAI scale score is the sum of scores and ranges from -10 to 10. The results may be dichotomized to positive subject response (scores > 0) or a negative (dysphoric) subjective response (scores < 0). A positive score on the DAI predicts medication compliance (Hogan *et al.*, 1983). According to (Hogan & Awad, 1992), the DAI predicted short-term antipsychotic medication treatment response as measured by the Brief Psychiatric Rating Scale (BPRS).

4. Stigma Scale of the Personal Beliefs about Illness Questionnaire (PBIQ)

The Personal Beliefs about Illness Questionnaire is intended to capture the degree to which clients felt that the social and scientific beliefs about mental illness are accepted by them (Birchwood, Mason, MacMillan, & Healy, 1993). The questionnaire has five scales, including the stigma scale. Stigma includes three questions that assess whether clients believe their illness is a social judgment against them. Each question is rated on a four-point scale: strongly disagree (1), disagree (2), agree (3), and strongly agree (4). The stigma scores

range from 3 to 12. Birchwood et al (1993) found in a sample of 18 individuals with schizophrenia and depression a mean stigma score of 7.5 and in a sample of 66 individual with schizophrenia and without depression a mean stigma score of 6.0. A lower score indicates a lower belief of stigma.

5. Calgary Depression Scale for Schizophrenia (CDSS)

The Calgary Depression Scale for Schizophrenia is a symptom scale that assesses depressive symptoms in people with schizophrenia (D. Addington *et al.*, 1990). It is administered by using a nine-item semi-structured interview. The last item is based on observations of the entire interview. The CDSS consists of nine items: 1) depressed mood, 2) hopelessness, 3) self-deprecation, 4) guilty ideas of reference, 5) pathological guilt, 6) depression worse in morning, 7) early wakening, 8) suicide, and 9) observed depression. The time frame is typically two weeks before the interview. Items are scored 0 = absent, 1 = mild, 2 = moderate, and 3 = severe. Total scores range from 0 to 27. A total score of five or higher may identify individuals at high risk for comorbid major depressive disorder. The CDSS depression score is obtained by adding each of the item scores. Construct validity of the tool has been confirmed with other depression scales (e.g. Hamilton Depression Rating Scale) and by the prediction of a depressive episode (D. Addington, Addington, & Maticka-Tyndale, 1992) Internal validity and inter-rater reliability of the scale has been shown to be good (D. Addington *et al.*, 1992). The CDSS has been specifically developed for the assessment of the level of depression in schizophrenia. It is recommended that the rater have experience with people with schizophrenia.

6. Global Assessment of Functioning (GAF)

The purpose of the Global Assessment of Functioning (GAF) Scale is to evaluate overall psychosocial functioning (Spitzer *et al.*, 1992). The GAF Scale is a 100-point single item rating scale that evaluates overall psychosocial functioning during a specified period of time on a continuum from psychological illness to health. The scale's values range from 0 to 100 representing the hypothetically sickest person to the hypothetically healthiest. The GAF was modified from the Global Assessment Scale developed by Endicott et al in 1976. The GAS was shown to be highly sensitive to change over time. The GAF scale is divided into 10 equal 10-point intervals (Table 4.3).

Table 4.3 Global Assessment of Functioning (GAF): intervals and descriptions

Interval	**Description**
81-100	These individuals do not have psychopathology and exhibit superior functioning which includes a wide range of interests, social effectiveness, warmth and integrity.
71-80	These individuals have minimal or no psychopathology but do not have many of the positive mental health features noted in the 81+ categories.
31-70	The vast majority of psychiatric outpatients are rated in this range.
1 – 40	The vast majority of psychiatric

Table 4.3 Global Assessment of Functioning (GAF): intervals and descriptions	
Interval	**Description**
	inpatients are rated in this range.
1 – 10	Treatment of these individuals is urgently needed.

7. Global Assessment of Relational Functioning (GARF)

The Global Assessment of Relational Functioning Scale is used to evaluate the individual's functioning in relationships with family, friends, and significant others. This scale rates the degree of relational functioning from "optimal" to "disrupted" by using the three major content areas of problem solving, organization, and emotional climate. The GARF was developed in 1996 by the Committee on the Family of the Group for the Advancement of Psychiatry (Group for the Advancement of Psychiatry 1996). The GARF Scale is represented in 20-point intervals (Table 4.4).

Table 4.4 Global Assessment of Relational Functioning (GARF): intervals and descriptions	
Interval	**Description**
81 – 100	Relational unit is functioning satisfactorily from self-report of participants and from perspectives of observers.
61 – 80	Functioning of relational unit is somewhat satisfactory. Over a period of time, many but not all difficulties are resolved without complaints.

Table 4.4 Global Assessment of Relational Functioning (GARF): intervals and descriptions	
Interval	**Description**
41 – 60	Relational unit has occasional times of satisfying and competent functioning together, but clearly dysfunctional, unsatisfying relationships tend to predominate.
21 – 40	Relational unit is obviously and seriously dysfunctional; forms and time periods of satisfactory relating are rare.
1 – 20	Relational unit has become too dysfunctional to retain continuity of contact and attachment.

8. Social and Occupational Functioning Assessment Scale (SOFAS)

The purpose of the Social and Occupational Functioning Assessment Scale is to evaluate overall social and occupational functioning (Goldman, Skodol, & Lave, 1992). The SOFAS, modified from the GAF scale, is a 100-point single-item rating scale that evaluates overall social and occupational functioning during a specified period of time on a continuum from psychological illness to health. The scale's values range from 0 to 100 representing the hypothetically sickest person to the hypothetically healthiest. The scale is divided into 10 equal 10-point intervals (Table 4.5).

Table 4.5 Social and Occupational Functioning Assessment Scale (SOFAS): intervals and description	
Interval	**Description**
91 – 100	Superior functioning in a wide range of activities.
81 – 90	Good functioning in all areas, occupationally and socially effective.
71 – 80	No more than a slight impairment in social, occupational, or social functioning (e.g. infrequent interpersonal conflict, temporarily falling behind in school work).
61 – 70	Some difficulty in social, occupational, or school functioning, but generally functioning well, and has some meaningful interpersonal relationships.
51-60	Moderate difficulty in social, occupational and school functioning (e.g. few friends, conflicts with peers or co-workers).
50 and below	Serious impairment in social, occupational, or school functioning (e.g. no friends, unable to keep a job).

9. Substance Use Rating Scale

The Substance Use Rating Scale evolved from the alcohol use scale developed by Drake and colleagues (1990). This rating scale is ordinal with five categories: 1) no use, 2) mild use, 3) moderate use, 4) severe use, and 5) extremely severe use. This rating scale is intended for use with individuals with

severe mental illness such as schizophrenia and related disorders, and severe bipolar and other mood disorders. A limitation of this rating scale is that it is not intended to serve the function of a comprehensive evaluation for the purpose of treatment planning (Drake, Osher, Noordsy, Hurlbut, Teague, & Beaudett, 1990).

4.5.3 Chart reviews: hospital and emergency room utilization

Chart reviews were conducted at the three tertiary hospitals located in the Saskatoon Health Region: Royal University Hospital (RUH), St. Paul's Hospital (SPH) and Saskatoon City Hospital (SCH). At the time of the study, only RUH and SCH had in-patient psychiatric units. Data on the use of hospital and emergency room services were collected retrospectively for each patient from entry to the EIP program for a period of two years, creating an acute care service profile. Similarly, data on the use of hospital and emergency room services were collected retrospectively for each patient in the historical group for a period of two years, starting with the first acute care presentation of first-break psychosis. Diagnostic imaging and laboratory usage was not tracked. The following data were collected for each patient:

- Royal University Hospital – number of psychiatric admissions
- Saskatoon City Hospital – number of psychiatric admissions
- Saskatoon Health Region – total number of psychiatric admissions

- Royal University Hospital – number of emergency room visits
- Saskatoon City Hospital – number of emergency room visits
- St. Paul's Hospital – number of emergency room visits
- Saskatoon City Hospital – total number of emergency room visits

- Royal University Hospital – total patient days

- Saskatoon City Hospital – total patient days
- Saskatoon City Hospital – total patient days

- Royal University Hospital – average Length of Stay
- Saskatoon City Hospital – average Length of Stay
- Saskatoon Health Region – average Length of Stay
- RUH certified admissions
- SCH certified admissions
- SHR certified admissions

- Number of justice/police encounters

- Number of suicide attempts

4.5.4 Cost analysis

Costs were calculated from the perspective of the Saskatoon Health Region (SHR). The cost per day for an in-patient psychiatric stay at Saskatoon City Hospital and Royal University Hospital were calculated based on information provided by the Saskatoon Health Region. The average cost for a psychiatric emergency room visit in the Saskatoon Health Region was provided by SHR for St. Paul's Hospital, Saskatoon City Hospital and Royal University Hospital. The costs included salaries of staff involved in direct patient care and facility operating costs such as nursing unit supplies, patient meals, and housekeeping. It did not include overhead costs such as management salaries or capital costs (buildings and equipment). Client utilization data, from the hospital chart reviews, was then used to calculate client-specific costs for the following:

- RUH Inpatient Cost

- SCH Inpatient Cost

- SHR Inpatient Cost
- RUH Emergency Room Cost
- SCH Emergency Room Cost
- SHR Emergency Room Cost
- Total acute care cost
- Early Intervention Program cost
- Total Saskatoon Health Region cost

4.5.5 Psychiatrist satisfaction survey

A questionnaire for measuring psychiatrists' satisfaction with their patients' progress in the Early Intervention in Psychosis Program were mailed to psychiatrists involved with 30 early intervention patients (*Appendix K*). Fifteen surveys were distributed in April 2003 and fifteen surveys were distributed in September 2004. The survey response rate was 73% (nine psychiatrists responded about 22 of 30 patients). This is consistent with other physician survey response rates reported in the literature, ranging from about 50 to 65 percent (Murff & Kannry, 2001; Murray, Montgomery, Chang, Rogers, Inui, & Safran, 2001).

4.5.6 Focus groups

As part of the mixed methods approach, two focus groups were included in the study design. The objective was to complement the quantitative data and to collect relevant information to support an "administrative review" of the Early Intervention in Psychosis Program.

Focus groups offer a number of important advantages. A key benefit of focus groups is the group dynamics which occur when the moderator stimulates discussion among the participants about a topic (Clarke, 1999; Morgan, 1997). This can generate new thinking about a topic that results in a much more in-depth discussion of the topic being covered (Clarke, 1999). The fact that people naturally interact and influence each other creates high face validity (i.e. does the measure appear relevant to the construct) (Lincoln & Guba, 1985).

A traditional focus group consists of a 90 -120 minute discussion among eight to ten individuals, who have been selected based on predetermined characteristics (Krueger & Casey, 2000). A “mini-group” is essentially the same as a traditional focus group except it generally consists of four to six participants (Krueger & Casey, 2000). A focus group is led by a trained moderator who conducts the session using an interview guide (Krueger & Casey, 2000). Clarke (1999) emphasized that it is important to give careful consideration to “the size of the group, the participants' backgrounds, the venue and the choice of moderator.”

Using a semi-structured interview guide, focus group interviews were conducted in June and September 2006 with key stakeholders to collect information on the design and evaluation of the Early Intervention in Psychosis Program (*Appendix L* – Interview Guide). Interviews were audio-taped and transcripts were generated by a research assistant with a background in mental health quality assurance. The research assistant and auditor were asked to sign a confidentiality agreement, and each participant signed a consent form. Transcripts were read and coded by the researcher, with an audit performed by

a Knowledge Translation Consultant, with an MBA in Health Services, from the Health Quality Council of Saskatchewan. Themes within and across interviews were identified and categorized, and the auditor's feedback was used to refine the thematic analysis (Lincoln & Guba, 1985). Results focused on themes that consistently emerged (Lincoln & Guba, 1985).

4.6 Data analysis

4.6.1 Quantitative analysis

Using SPSS for Windows Version 15.0, a database of the EIP client assessments and the hospital chart reviews was developed. To ensure alignment with the Program Logic Model, each measure under analysis was matched to the corresponding Goal/Effect of the logic model. Descriptive and inferences analysis was completed. Analyses of variance statistics were used for testing group mean differences, and repeated measures tests were conducted for the respective timeframes.

4.6.2 Qualitative analysis

Content analysis was used to analyze the open-ended questions from the psychiatrist survey and the transcripts from the focus groups. This method is used to analyze the presence, meaning and relationship of words and concepts, and to make inferences (Morgan 1997). Content analysis is used in many academic disciplines, including anthropology, communications, literature, marketing, political science, psychology, sociology, and other fields (Morgan, 1997). Conceptual analysis is a primary component of content analysis. In

conceptual analysis, the analysis involves quantifying and tallying the presence of the concept (Morgan, 1997). Also known as thematic analysis, the focus is on looking at the occurrence of selected themes (Morgan, 1997). Content analysis was done manually by reading through the transcripts and writing down concepts as they occurred. The issues of reliability and validity in content analysis are similar to those addressed in other research methods. The reliability of content analysis refers to stability, reproducibility and accuracy of coding (Morgan, 1997). The validity of a content analysis refers to the correspondence of the categories to the conclusions, and the ability to generalize the results to a theory (Morgan, 1997).

4.6.3 Data analysis challenges

4.6.3.1 Handling missing values

A battery of tests was used to assess EIP clients at baseline, six months, 12 months, 18 months and two years. Missing data are common in many psychiatric studies, especially when subjects are followed over time (Streiner, 2002). Missing data were a serious problem with the assessments of the EIP clients. The number of clients assessed ranged from the full group of 29 (e.g. baseline assessment of the Substance Use Rating Scale) to a low of 16 (e.g. one year assessment of the Substance Use Rating Scale). There was no clear pattern for missing data and differing subsets of clients were represented at various data points. In some instances, the validity of a study is jeopardized because subjects are lost to follow-up and they rarely represent the group as a whole (Streiner, 2002). This was not the case in this data set. The clients with

missing values were not completely “lost to follow-up” but in all cases finished the full two-year program and had some data elements collected (i.e. all clients remained regular participants of the program, receiving services from the program but not all assessments were completed as scheduled). Rather, the missing data appear to be a factor of the heavy workloads of the two mental health nurses responsible for the data collection.

University of Toronto researcher Streiner (2002) discusses several approaches to handling missing data. These methods include: 1) replacement with the group mean; 2) regression estimates; 3) multiple imputation; 4) last observation carried forward (LOCF); and 5) growth curve analysis. He noted that some may result in biased estimates of the treatment effect, and others may overestimate the significance of the statistical tests.

From a nursing research perspective, Kneipp and McIntosh (2001) discuss the challenge of addressing missing values. They address the common approaches for handling missing data including complete-case analysis, available-case analysis, and single-value imputation methods. They note that “these methods have been the subject of increasing criticism with respect to their tendency to underestimate standard errors, overstate statistical significance, and introduce bias” (Kneipp & McIntosh, 2001, p. 385). The authors review the limitations of standard approaches for handling missing data, and present multiple imputation a useful method for nursing research. Using secondary analysis of a data set that had a large degree and complex pattern of missing data, the authors present multiple imputation as a more appropriate

method for conducting data analysis and avoiding the bias associated with other methods of handling missing values.

The high number and irregular pattern of missing values jeopardized the validity of this part of the EIP study because of reduced power to detect differences. Furthermore, the clients assessed at each time frame represented a shifting sub-group of clients (e.g. using Medication Adherence as an example, the clients assessed at year one were not the same clients assessed at year two). To accommodate this discrepancy, consistent case base analysis was used but this further reduced the power to detect effects. As well, it is difficult to find a statistical difference between the measurement periods because the standard deviation and standard error differences are quite large.

Given the limitations of the imputation methods, it was decided to not impute the missing values for the following reasons (Little & Rubin, 1987):

1. Multiple imputation – Most techniques available for creating multiple imputations assume that the missing values are missing at random. In other words, it is assumed that missing data values carry no information about probabilities of "missingness." Given that the EIP clients were experiencing first-break psychosis, it could be argued that the missing data were not purely random but rather were the result of some other factor (e.g. the client's compliance or clinical status at that particular data collection point).
2. Case-deletion – Case-deletion strategies have a number of shortcomings. For example, if the discarded cases form a representative and relatively small portion of the entire dataset, then case deletion may be a

reasonable approach. However, case deletion generally leads to valid inferences only when missing data are missing completely at random. In other words, case deletion assumes that the discarded cases are like a random subsample. When the discarded cases differ systematically from the rest, estimates may be seriously biased. As discussed above, the discarded cases might be systematically different as a result of some client factor (such as compliance or clinical status). Furthermore, case deletion often results in a large portion of the data being discarded and an unacceptable loss of power. This was the case with the EIP data set which showed missing value levels as high as 41 percent.

3. Single imputation – If the proportion of missing values is small, single imputation may be quite reasonable. Without special corrective measures, single-imputation inference tends to overstate precision because it omits the between-imputation component of variability. When the fraction of missing information is small (e.g. < 5%) then single-imputation inferences may be fairly accurate (Little & Rubin, 1987). However, in some cases, even small rates of missing information may seriously impair a single-imputation procedure. Again, as stated above, the EIP data set showed missing value levels that far exceed the recommend 5 percent level.

4.6.3.2 Statistical versus clinical significance

It is acknowledged that some of the clinical outcomes in this study were suggestive, although not statistically significant. In general, treatment effects

are determined on the basis of statistical comparisons between mean changes to pre and post-treatment measures (Jacobson & Truax, 1991). Statistical effects identify real differences as opposed to ones that are unreliable, questionable or the result of chance (Jacobson & Truax, 1991). The existence of a treatment effect does not necessarily equate to clinical significance. When the treatment effect does not exist in the statistical sense, however, it could still have clinical significance (Jacobson & Truax, 1991). Clinical significance refers to the benefits derived from the treatment, and its impact on clients and their lives (Jacobson & Truax, 1991). Clinical judgment, supported by mathematical calculations, is required to assess whether an observed difference is clinically meaningful. Jacobson and team (1999) noted that methods for defining and determining the clinical significance of treatment effects may be limited for chronic mental health disorders such as schizophrenia because the likelihood of returning to "normal" functioning is limited. For this clinical population, methods to calculate clinical significance may not be applicable if the clinical "cutoff point" is not feasible (Jacobson *et al*, 1999). Given the methodological limitations of this approach and the administrative focus of this study, clinical significance was not calculated.

5.0 PSYCHOSIS CARE: LOCAL DESCRIPTION AND CONTEXT

This chapter describes the traditional model of care (1990-1998) and the early intervention model (1999-2006). To provide further context, it describes other community-based services available within the Saskatoon Health Region during the time period of the case study.

5.1 Psychosis care in the Saskatoon Health Region

5.1.1 Traditional model: 1990 to 1998

During the case study's first time period (1990 to 1998), psychotic disorders in the Saskatoon Health Region, including first-break psychosis, were treated using a decentralized model of service delivery. In 1990, more than a dozen organizations were involved in providing mental health services to Saskatoon and district. The Saskatoon Health District was formed in 1992, and brought about the amalgamation of a number of health services including acute care, home care and nursing home care (Saskatoon Health Region, 2006). In 1994, the Saskatchewan government started to devolve provincially-operated community mental health services to the locally-governed health districts including Saskatoon. As a result, Saskatoon District Mental Health Services was formed between 1994 and 1996 by the integration and consolidation into one service of three formerly discrete organizations: Royal University Hospital,

Saskatoon City Hospital and Saskatchewan Health (Saskatoon Health Region, 2006). In addition, the Department of Psychiatry at the University of Saskatchewan's College of Medicine worked and continues to work closely with Mental Health Services to carry out a shared commitment to teaching, research and service (Saskatoon Health Region, 2006).

Despite this integration of services at the governance level, early psychosis care was fragmented and disjointed at the service level. In this decentralized approach, mental health treatment consisted of a variety of health and social service providers and volunteers organized into a decentralized system of services (Health Canada, 2002). This included a combination of psychiatrist and family physician care, hospital-based services (at Royal University Hospital and Saskatoon City Hospital), psychiatric rehabilitation home care, and community support provided by community-based non-profit organizations (see subsequent section 5.1.3 for details). Psychiatrists and other mental health professionals worked with family physicians, providing support and counselling assistance in out-patient, in-patient and home-based settings.

This fragmented approach can make it difficult for service providers to work as a team to ensure continuity of care. For most Canadians, the primary care physician is their first and sometimes only contact with the health care system (Health Canada, 2002). In other cases, the hospital emergency department is the individual's first point of contact with the mental health system and acts as a resource for crisis intervention (Health Canada, 2002). For maximum effectiveness, a treatment system should provide individuals with access to services "where and when needed" (Noseworthy, McGurran, &

Hadorn, 2003). Unfortunately, this was not always the case and waiting lists for certain services developed especially in mental health services for children and adolescents (Noseworthy *et al.*, 2003). During this time period, Saskatoon experienced a severe shortage of child psychiatrists which created delays in responding to requests for consultations.

Historically, mental health patients were treated almost exclusively in institutional settings. The reform of the Canadian mental health system[14] in the 1960s and 1970s reduced the number of beds in psychiatric institutions (Hartford, Schrecker, Wiktorowicz, Hoch, & Sharp, 2003; Sussman, 1998). During this period of reform, many individuals with severe mental illness, including psychosis, moved from psychiatric institutions into general hospitals or directly to the community (Hartford *et al.*, 2003). Community-based programs, which help individuals live productive and meaningful lives, became an essential and cost-effective alternative or complement to hospital-based care (Health Canada, 2002).

At times, hospitalization of individuals with a psychotic disorder still becomes necessary. Hospitalization for psychosis can assist in diagnosis and can stabilize symptoms (Health Canada, 2002). The hospital also serves as a safe and supportive environment when the risk of suicide is high or judgment is severely compromised (Health Canada, 2002). Hospitalization provides important short-term respite for care providers. Planning for the person's transition back into community living is an important role of the hospital team,

[14] For a good summary of mental health reform in Canada over four decades (1959-2000) refer to Hartford, K., T. Schrecker, et al. (2003). "Four decades of mental health policy in Ontario, Canada." Administration and Policy in Mental Health **31**(1): 65-73.

which is carried out in cooperation with care providers and service agencies in the community.

Mental health services in Saskatoon kept pace with industry-wide developments and advances. In the past half century, progress has been made in the treatment of schizophrenia and other psychotic disorders (Falloon, Held, Roncone, Coverdale, & Laidlaw, 1998). This occurred primarily because of the discovery of antipsychotic drugs, advances in psychosocial interventions, and the development of stress management techniques (Falloon *et al.*, 1998). Despite the demonstrated benefits of combined drug and psychosocial treatment, prior to the advent of the early intervention movement in the 1990s, there were few clinical programs that offered comprehensive and consolidated early psychosis services (Falloon *et al.*, 1998).

Proponents of early intervention assert that traditional models, such as the one in place in Saskatoon during the 1990s, were directed towards the needs of older patients with chronic conditions (Edwards & McGorry, 2002). These methods, they argue, reinforce the pessimism associated with the treatment of schizophrenia and other psychotic disorders. Early intervention fosters a more holistic approach by not focusing simply on florid psychotic symptoms (Edwards & McGorry, 2002). Critics of the traditional system contend that early intervention, a more comprehensive and intensive early response system, is needed for individuals with first-break psychosis. This re-thinking of psychosis care in the Saskatoon Health District prompted the creation of an Early Intervention in Psychosis program in 1999.

5.1.2 Early intervention model: 1999 to 2006

The Early Intervention in Psychosis (EIP) program in Saskatoon[15], launched in May 1999, was modeled after other domestic and international early intervention in psychosis programs. The Saskatoon EIP program is situated within Mental Health Rehabilitation and Adult Community Services, in the Mental Health and Additions Care Group and operates in consultation with the joint Department of Psychiatry of the Health Region and the University of Saskatchewan. The SHR EIP program provides intensive intervention for individuals with first-break psychosis. The program integrates the psycho-social treatment team with referring family physicians and psychiatrists, as well as family members and significant others. It serves a catchment population of about 300,000.

Following a one-year planning and consultation phase, the Early Intervention in Psychosis program was launched on May 15, 1999. A communication strategy to inform and educate local family physicians and psychiatrists took place in spring 1999 to introduce the program and its services to the Saskatoon district medical community. The core program team consisted of two consultant adult psychiatrists and two registered psychiatric nurses with significant experience in case management and community mental health nursing. This took place without incremental resources, by re-allocating the time of two psychiatric nurses from the SHR Mental Health Rehabilitation Program. At this time of inception, it was not known exactly how many clients would be

[15] Saskatoon District Health, formed in 1992, expanded into the larger Saskatoon Health Region in 2002 (Saskatoon Health Region, 2006).

referred and admitted to the program. As a result, the psychiatric nurses maintained a number of clients from their previous rehabilitation case load. This was intended to be a transitional strategy to accommodate the “ramp up” of the EIP program. The community mental health nurses had caseloads averaging 35 to 40 clients. Over time, periodic support was provided by a neuro-psychologist. Later in the program’s development, a child psychiatrist became involved on a part-time basis. In other jurisdictions, more generously funded services offer an increased level of clinical psychology, occupational therapy, social work, family work and psychometric support (Ehmann *et al.*, 2004).

This two-year outpatient program provides psychiatric consults and mental health nursing to adolescents and young adults experiencing first episodes of psychosis. Key clinical components include medical and pharmacological management, psycho-education (individual and group) for both clients and family members, and skill building (coping, stress management, problem solving). These components, with their corresponding goals/effects, are represented in the Program Logic Model presented earlier in section 3.4 (Appendix I). The program utilizes a modified assertive case management approach.

The program defines “first episode” as the first illness occurrence for clients who had not received more than two years of treatment prior to referral to the program. The exclusion criteria are those individuals with a psychosis known to be related primarily to substance use disorder or a defined acquired brain disorder. People within the region experiencing first-episode non-affective psychosis were to be referred to the EIP for rapid evaluation, treatment and

rehabilitation. Referrals to the program must be made through family physicians or psychiatrists (often via the hospital emergency department or in-patient psychiatric service) by means of Central Intake, the health region's mental health admission service for community-based care. Referrals are first contacted by telephone and the attempt is made to see the person within 72 hours. Clients can utilize Early Intervention services for up to two years, at which time they are discharged and referred to other mental health programs and/or to the care of their family physician.

At present, most Early Intervention Programs, including the Saskatoon program, focus on secondary prevention. This means that effective treatment is given as soon as possible after the development of the first episode of psychosis (Jackson & Birchwood, 1996). Early intervention services share many common characteristics, including goals, selection criteria, assessments, interventions, and staffing (Table 5.1).

Table 5.1 SHR early intervention goals.

1) early identification and treatment of psychosis;
2) promotion of early recovery;
3) minimization of relapse;
4) reduction of stress for families and caregivers;
5) promotion of personal control over psychosis;
6) promotion of normal psychosocial development.

Adopted from Edwards & McGorry (2002)

Evidence of first-episode psychosis, such as hallucinations, delusions, thought disorder or gross behavioural disturbance, is the primary selection

criterion for Early Intervention (Edwards & McGorry, 2002). Most EIP programs have age restrictions (commonly ages 16 to 30) (Edwards & McGorry, 2002). The SHR program has a minimum age of 14 and no upper age limit. In general, clients are given a low dose neuroleptic medication regime, cognitive therapy for hallucinations and delusions, and specific psychosocial interventions for personal and social recovery (Edwards & McGorry, 2002). These interventions place emphasis on the establishment of appropriate goals and promotion of self-management techniques. Most EIP Services have strong family support programming, and this was the intention of the Saskatoon program as well. Early in its operation, the program offered a series of six-session family groups that focused on psychoeducation.

Inpatient treatment for Saskatoon EIP clients follows the Canadian Clinical Practice Guidelines. Patients are admitted to either Royal University Hospital or Saskatoon City Hospital. The goal for inpatient treatment is to: 1) assess, stabilize and treat the client; 2) provide families/caregivers with support and preliminary education and 3) refer the client and family/caregivers to appropriate services. The EIP team provides collaboration and follow-up for those clients currently registered in the EIP program and subsequently admitted to an inpatient unit.

Symptom severity and general impairment are measured at admission to the service and repeated periodically to measure the client's progress. Clinical rating scales used include Positive and Negative Symptom Scale (PANSS), the Global Assessment of Functioning (GAF), the Global Assessment of Relational Functioning (GARF), Social and Occupational Functioning Assessment Scale

(SOFAS), duration of untreated psychosis (DUP), quality of life scales, Calgary Depression Scale, caregiver burden, and substance use reporting. In addition to clinical management, these measures are intended to be used for program evaluation and research.

During the second time period of the case study (1999-2006), the Saskatoon health district and its programs and services continued to evolve. In December 2002, Mental Health Services and Addiction Services were amalgamated as one Care Group under one General Manager (Saskatoon Health Region 2007). Mental Health and Addiction Services is one of several Care Groups coordinated and organized within the Saskatoon Health Region (Saskatoon Health Region, 2007). This was a positive move for early psychosis care, both conceptually and practically, given the high prevalence of substance abuse co-morbidity in this client group. Strengthened linkages between the EIP program and Addictions Services were discussed but not formalized. It should be noted that when the Early Intervention in Psychosis program was launched in 1999, the program planners did not include addiction programming. In fact, one of the program's exclusion criteria involved substance-induced psychosis. It would appear the EIP program underestimated the impact of co-morbid substance abuse on this client group.

5.1.3 Saskatoon Health Region: other mental health services

Other out-patient services are offered by the Saskatoon Health Region to support individuals with mental illness. These include:

Children and Youth Services

Within the SHR Mental Health Services, Children Services are provided to children up to 12 years of age and their families. Youth Services are provided to adolescents from 13 to 18 years of age and their families. In 2003, the EIP started working more closely with the SHR Children and Youth Services. This service relationship was developed to alleviate some of the pressure experienced by the Early Intervention team. It was agreed that the Children and Youth Services team would provide some of the counselling to families who have children in the EIP program. This was in response to a reduction in family programming by the EIP team as a result of workload pressures. In addition, a child psychiatrist agreed to provide consultative support to the EIP program for clients ages 14 to 18.

McKerracher Centre

McKerracher Centre offers day and evening programs for adults ages 18 and over. It serves two primary client groups:

- Individuals who have suffered a significant loss of social functioning for a period generally exceeding 18 months as a result of a mental health disorder; and
- Individuals at risk of becoming chronically disabled by a mental health disorder, including persons who are acutely ill or traumatized.

McKerracher provides a structured and time-limited educational program. Topic areas include goal setting, social or communication skills, medication management, illness awareness, education and coping, assertiveness training, understanding depression and anxiety management (Saskatoon Health Region,

2007). McKerracher emphasizes services for people who have chronic or long-term mental health illnesses. Examples include bipolar affective disorder, delusional disorder, depression, and schizophrenia and other psychotic disorders. This programming provides important support to clients upon discharge from the EIP program.

5.1.4 Community-based mental health services

A number of non-Saskatoon Health Region community-based mental health services are available in Saskatoon to support clients with mental illness. The Early Intervention in Psychosis program commonly refers clients to these community-based programs. These include:

Canadian Mental Health Association (Saskatchewan Division)

Founded in 1950, the Canadian Mental Health Association (Saskatchewan Division) is a volunteer-based organization that “supports and promotes the rights of persons with mental illness to maximize their full potential; and promotes and enhances the mental health and well-being of all members of the community" (Canadian Mental Health Association, 2007). One of the primary programs of the Canadian Mental Health Association (Saskatchewan Division) is Friends for Life. This program offers information and support through presentations, resources and personal contact. It promotes “development of the knowledge and skills necessary for the enjoyment of social and emotional health.” Friends for Life delivers presentations to students, teachers, health professionals and the general public throughout the province. It also conducts newspaper and media interviews to reach the general public.

Friends for Life offers workshops in Applied Suicide Intervention Skills Training (ASIST). Other services include (Saskatoon Health Region, 2006):

Social Development: Social/Recreation Volunteer Coordinator

- Drop in centre
- Scheduled leisure and recreation activities
- Health promotion and educational programs
- Creative arts programs
- Special events - trips, tours, dances, socials
- Community Friends - a one-to-one match with a community volunteer for friendship and support
- Programs provided by community volunteers

Vocational Rehabilitation: Vocational Counsellor

- One-to-one counselling to assist individuals with evaluating abilities and interests
- Assistance with returning to employment
- Assistance with returning to or continuing with education
- Long term support on the job or in school
- Referral agency for Employment Assistance for People with Disabilities (EAPD)

Life Skills: Life Skills Coach

- A five-month program for people preparing for employment: ten weeks classroom, ten weeks work placement
- Helps individuals develop skills in dealing with and coping with daily living situations
- Participants accepted by referral only (must be connected with Mental Health Services)

Crocus Co-op

Crocus Co-op is a non-profit member-driven organization comprised of adults recovering from mental illness. Its philosophy revolves around individual and collective empowerment. Crocus Co-op works to help its members “direct and control their own lives.” It assists in the development of support services that improve the lifestyles of its members in areas of rehabilitation including

improved economic conditions, employment training, recreation, social activities and education. Crocus Co-op programs include:

- drop in centre
- social activities
- member support
- computer centre
- resource library
- community work program
- in-house promotional button manufacturing
- hot meal program (lunch and supper at reduced cost)
- used clothing and furniture depot
- recreational activities
- transitional employment program

Saskatoon Crisis Intervention Service, Crisis Management Service

Crisis Management Service (CMS) is a "specialized mental health service for individuals who are severely behaviourally impaired and have problems maintaining connection with other services" (Saskatoon Health Region, 2006). This target group is often described as difficult to manage, or hard to serve (Saskatoon Health Region, 2006). CMS staff, referred to as Crisis Management workers, provide a spectrum of services to these individuals and their supports. Direct services include:

- Crisis intervention
- Assessment
- Service coordination
- Crisis management
- Assertive outreach

Crisis Management workers assist with meeting treatment needs and basic needs (such as financial, shelter, etc.). Crisis Management Service strives to facilitate the successful engagement or re-engagement of these individuals by mainstream services (Saskatoon Health Region, 2006).

Saskatoon Housing Coalition

The Saskatoon Housing Coalition celebrated its 20th anniversary in 2003 (Saskatoon Health Region, 2006). The Coalition offers Group Home and the Supportive Apartment programs that involve structured programming to enhance life skills and foster independent living. Supports for people in the community, through the Outreach program, include life skills orientation, illness awareness training, advocacy, and counselling for adults. The Coalition operates three apartment blocks with a total of 56 apartments (furnished and unfurnished suites) with staff available Monday to Friday, 9:00 - 5:00 pm. The Coalition also operates a five-bed group home, staffed 24 hours a day, seven days a week.

Schizophrenia Society of Saskatchewan (Saskatoon Chapter)

The Schizophrenia Society of Saskatchewan is a non-profit, charitable organization founded in 1982 by families and friends of people with schizophrenia (Schizophrenia Society of Saskatchewan, 2006). Services include:

- Family support groups
- Counselling and information
- Public awareness and education
- Advocacy
- Research

6.0 RESULTS

6.1 Description of client groups: early intervention and historical

In its first two years of operation (1999-2001), the Early Intervention Program admitted 43 clients with first-break psychosis, and 29 of these clients consented to participate in the EIP study (Table 6.1).

Table 6.1 Client demographic characteristics of SHR early intervention in psychosis study

Characteristic	**Early Intervention Program Evaluation n = 29**
Sex: Female Male	 7 (24%) 22 (76%)
Age (mean)	21.2 year (range 14 – 41)
Marital Status	28 – single 1 – divorced
Diagnosis: Schizophrenia Schizoaffective Disorder Psychosis NOS* Psychosis - Substance Induced Mood Disorder (with Psychotic Features) *** not otherwise specified**	 58.6% 6.9% 13.8% 3.4% 17.2%

The characteristics of the historical clients are outlined in Table 6.2 (below).

Table 6.2 Client demographic characteristics of SHR traditional model of care group for the historical period (1991 – 1998)

Characteristic	**Historical Period (HP) n = 14**
Sex: **Female** **Male**	 1 (14%) 13 (86%)
Age (mean)	25.8 years (range 15 – 44)
Marital Status	n/c
Diagnosis: Schizophrenia Schizoaffective Disorder Psychosis NOS* Psychosis - Substance Induced Mood Disorder (with Psychotic Features) *** not otherwise specified**	 71.4% 7.1% 14.3% 7.1% 0%

As predicted by the literature, schizophrenia was the most prevalent psychotic disorder in the study group: nearly 60% of EIP patients and 74% of historical clients. According to Health Canada (2002), the onset of schizophrenia typically occurs between the late teens and mid-30s, and onset before adolescence is uncommon. This was consistent with the EIP cohort's mean age of 21 (range 14 to 41). The historical group had a slightly higher mean age of 25.8 years (range 15 to 44) possibly due to a longer period of untreated psychosis. Studies show that men and women are affected equally by

schizophrenia and other psychotic disorders, but men usually develop the illness earlier than women (Loranger, 1984). This may explain the heavy representation of males: 76% in the EIP program and 86% in the historical group. The proportion of schizophrenic patients with a co-morbid drug and/or alcohol use disorder varies tremendously in published studies from as low as 50% to as high as 80% (Lehman *et al.*, 2000; Rabinowitz, Bromet, Lavelle, Carlson, Kovasznay, & Schwartz, 1998). Of the 29 EIP clients, 16 (55%) had a co-morbid drug and/or alcohol problem. The number of clients in the historical group with co-morbid substance abuse is not known.

6.2 Results matrix: structure, process and outcome

In keeping with the study's conceptual framework, the results are categorized as structure, process and outcome within the following results matrix (Table 6.3).

Table 6.3 Categorization of results by quality domain: structure, process and outcome.

Structure	**Process**	**Outcome**
Evaluability Assessment	Evaluability Assessment	-
-	-	EIP Client Assessments
-	Utilization of in-patient and emergency room services	Cost of in-patient and emergency room services
-	Psychiatrist Survey	Psychiatrist Survey
Focus Group Sub-themes: Structure	Focus Group Sub-themes: Process	Focus Group Sub-themes: Outcome

6.3 Assessment of early intervention clients

The EIP client measurements were matched to the corresponding Goals/Effects of the Program Logic Model (*Appendix I*) in order to achieve a comprehensive depiction of the Early Intervention in Psychosis Program, including clinical outcome, acute care utilization and costs.

The first Goal/Effect that was explored was “Improve Individual’s Ability to Manage Medication” which is at the Immediate level. The measures linked to this Goal/Effect are: 1) Adherence to medication; 2) Reason for non-adherence to medication; and 3) Drug Attitude Inventory. Client adherence to medication regimen did not change significantly over the two year study period. Good adherence (“takes medication as prescribed”) remained relatively stable over the three measurement periods (Table 6.4) - Baseline (71.4%), One Year (72.7%) and Two Year (76.5%). However, it is recognized that client self-report measures are subject to difficulties including (but not limited to): 1) a failure to elicit a thoughtful response; 2) biased by patients' mood; 3) affected by client’s choice of judgment strategies; and 4) patients' fear and apprehension (Hanita, 2000). With respect to non-adherence to medication regimen, the study looked at cost, belief/attitude, side effects, characteristic of disease, resistance to treatment and lack of social support. Across the three measurement periods, there was no consistent reason for non-adherence.

Table 6.4 Medication adherence of EIP clients at baseline, one year and two years.					
Timeframe	Never takes	Rarely takes	Occasionally Takes	Usually Takes	Takes Medication as Prescribed
Baseline (n=28)	3.6%	3.6%	10.7%	10.7%	71.4%
One Year (n=18)	9.1%	0%	9.1%	9.1%	72.7%
Two Years (n=18)	11.8%	0%	11.%	0%	76.5%

The Drug Attitude Inventory (DAI) shows that the client's subjective attitudes toward medication usage on average remained positive over the two-year study period (Fig. 6.1). At baseline, 76% of assessed clients scored "positive" and 24% of assessed clients scored "negative." At two years, 100% of assessed clients scored "positive." The DAI is a useful tool to include in the assessment of EIP clients. However, given the plateau effect after six months, it would be more cost effective to use this measure at three data collection points baseline, one year and two year) rather than at all five.

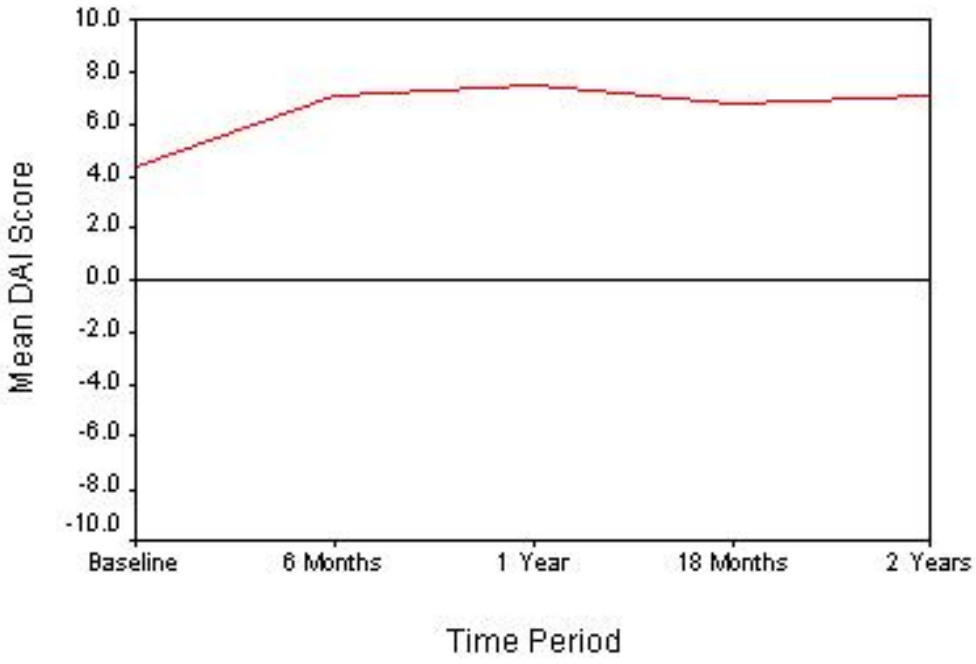

Figure 6.1 Drug Attitude Inventory (DAI) of EIP clients at baseline, six months, one year, 18 months and two years – consistent case base (n=17).

The **second** Goal/Effect to be explored is "Reduce Misconceptions about Psychotic Disorders" which is at the Intermediate level. The measure linked to this Goal/Effect is the Personal Beliefs about Illness Questionnaire – Stigma Scale. Overall, the stigma scores changed very little across the three time periods (Fig 6.2). The changes in scores for consistent cases were: baseline (6.90), one year (6.26) and two years (7.14). The EIP clients had some personal belief about stigma but it remained consistently low throughout the two year study period.

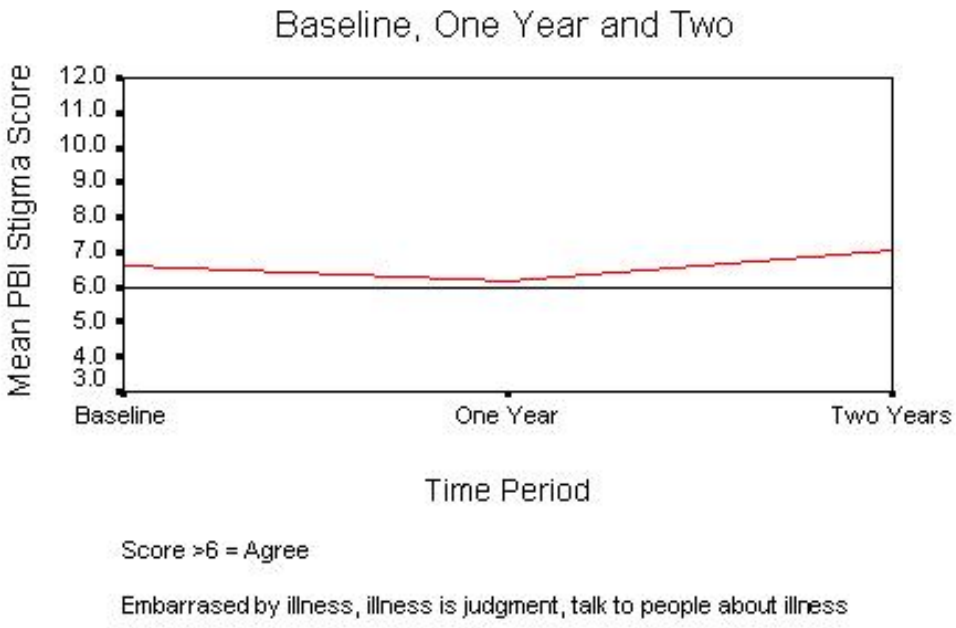

Figure 6.2 Personal Beliefs about Illness (PBI) – stigma scores of EIP clients at baseline, one year and two years – consistent case base (n=20).

The **third** Goal/Effect to be explored is "Improve Ability to Manage Stress" which is at the Intermediate level. The measure linked to this Goal/Effect is the Substance Use Rating Scale. Based on this measure, "no use" and "mild use" of substances by EIP remained relatively constant over the two-year period (Table 6.5). Severe substance use appeared to decrease during the second year of the program. As mentioned previously in the medication adherence discussion, these client self-report measures are subject to difficulties such as being influenced by clients' mood and being affected by their choice of judgment strategies (Hanita, 2000).

Table 6.5 Substance use rating scale scores: EIP clients at baseline to 24 months.

Category	Time Period				
	Baseline n = 29	6 months n = 20	12 months n = 16	18 months n=19	24 months n=18
No use	45 %	60%	88%	47%	33%
Mild use	17%	25%	12%	53%	56%
Moderate use	14%	5%	0%	0%	11%
Severe Use	24%	10%	0%	0%	0%
Extremely Severe Use	0%	0%	0%	0%	0%
Total	100%	100%	100%	100%	100%

(Drake *et al.*, 1990)

The **fourth** Goal/Effect to be explored is “Reduce the Burden and Stress on Self and Family” which is at the Intermediate level. The measures linked to this Goal/Effect include the Global Assessment of Functioning (GAF) scale and the Global Assessment of Relational Functioning (GARF) scale.

The mean EIP score for the Global Assessment of Functioning scale improved from 57.1 at baseline, to 73.0 at one year and 70.5 at two years (Fig. 6.3). The vast majority of psychiatric outpatients are rated in this range (31-70). The test using consistent cases (n=25) showed a significance level of $p<.05$ (sig=.023), therefore the three repeated GAF scores are significantly different taking into account the within-subjects effects.

The primary improvement in mean GAF score appeared between the baseline measure (mean GAF 57.9) and the year one measure (mean GAF 73.1), and then appeared to level off between year one and year two (mean GAF 70.8). The one year measure does not fall within the upper limit of the 95% CI of the baseline measure (65.6), thus confirming the conclusion that this group

of clients collectively improved their GAF scores from baseline to year one. A client with a GAF score of 57.9 would exhibit moderate symptoms such as flat affect and circumstantial speech, and occasional panic attacks. This type of client would have moderate difficulty functioning in social, occupational or school settings, for example with few friends, and perhaps conflicts with co-workers. In the case of a client with a GAF score of 73.1 or 70.8, if symptoms were present they would be transient and expectable reactions to psychosocial stressors, for example difficulty concentrating after a family argument.

These mean GAF scores at baseline (57.9), one year (73.1) and year two (70.8) are characteristic of normative scores for the vast majority of patients receiving psychiatric outpatient treatment (scores between 31-70). These clients do not appear to require inpatient care (average GAF score below 40), which indicates that the Early Intervention Program is an appropriate setting of care for these patients given their functional assessment. Individuals with scores 71 - 80 (similar to the year one and year two mean scores of 73.1 and 70.8 respectively) have minimal or no psychopathology but do not have many of the positive mental health features noted in the 81+ categories.

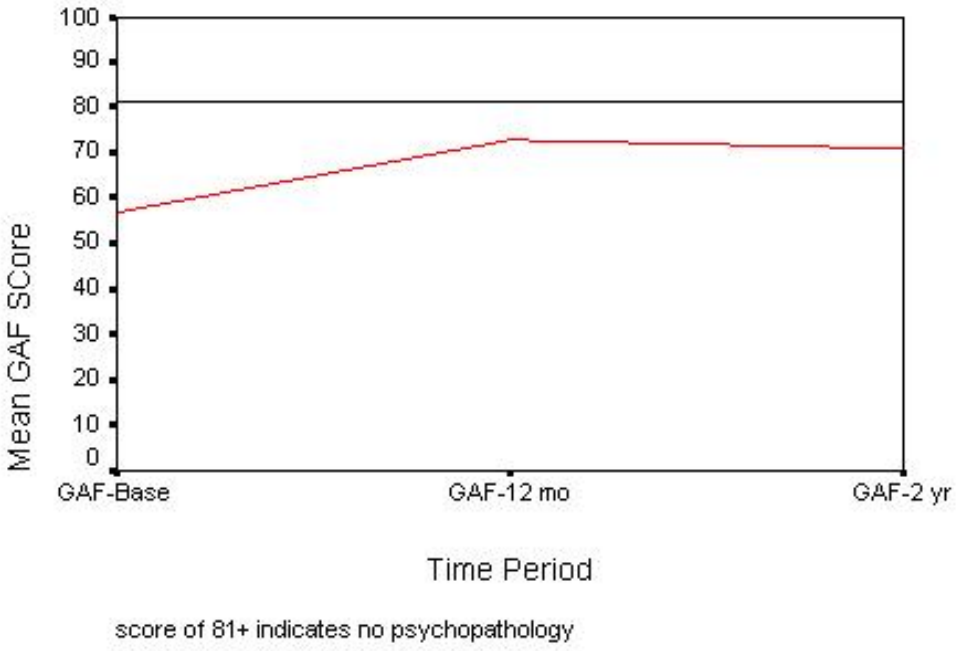

Figure 6.3 Global Assessment of Functioning (GAF) – EIP clients at baseline, one year and two years – with consistent case base (n=25).

The Global Assessment of Relational Functioning (GARF) Scale is used to evaluate the individual's functioning in relationships with family, friends, and significant others. The mean GARF scores for the EIP clients did not change appreciably over the two year study period (Fig. 6.4). Overall, GARF scores in this range (low to mid-70s) would describe an individual in which the "functioning of the relational unit is somewhat unsatisfactory." Daily routines are present but there is some pain and difficulty responding to the unusual. Some conflicts remain unresolved, but it may not disrupt the family functioning.

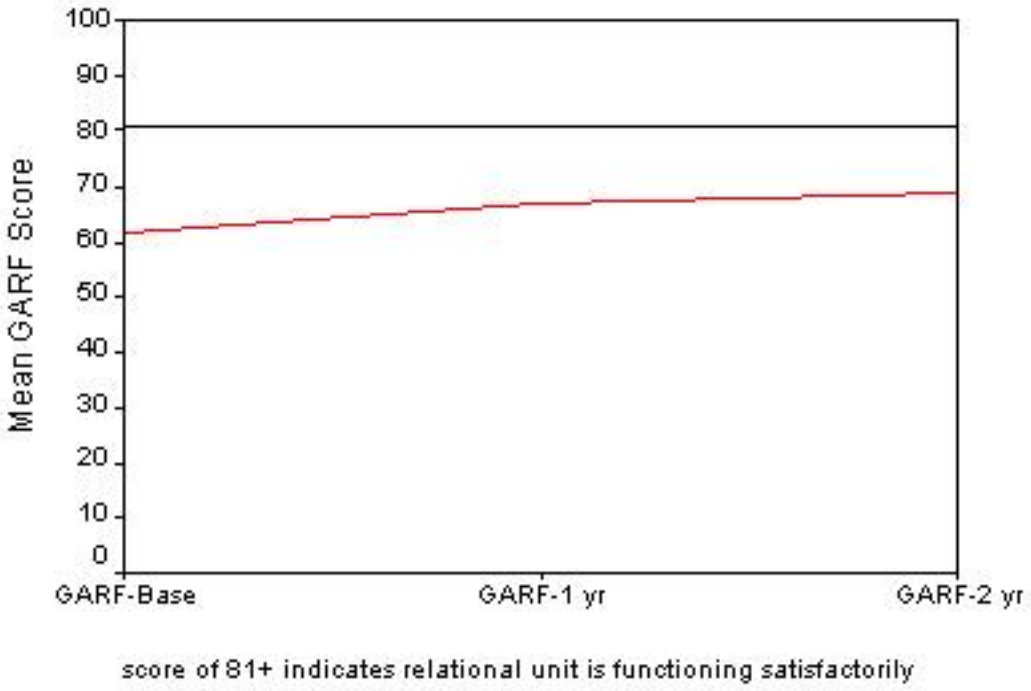

Figure 6.4 Global Assessment of Relational Functioning (GARF) – EIP clients at baseline, one year and two years – with consistent case base (n=25).

The **fifth** Goal/Effect to be explored is "Reduce Primary Symptoms of Psychotic Disorder (Duration and Severity)" which is at the Intermediate level. The measures linked to this Goal/Effect are the Positive and Negative Symptoms Scale (PANSS) (Fig. 6.5, Fig. 6.6 and Fig. 6.7) and the Calgary Depression Scale for Schizophrenia (Fig. 6.8).

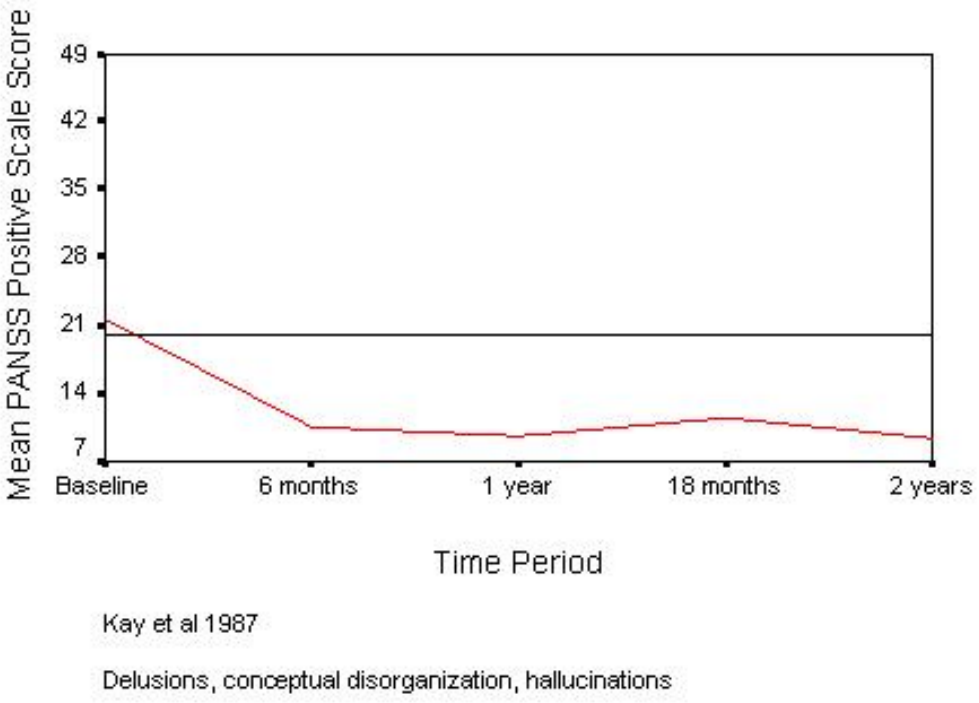

Figure 6.5 PANSS positive scale – EIP clients at baseline, one year and two years – with consistent case base (n=25).

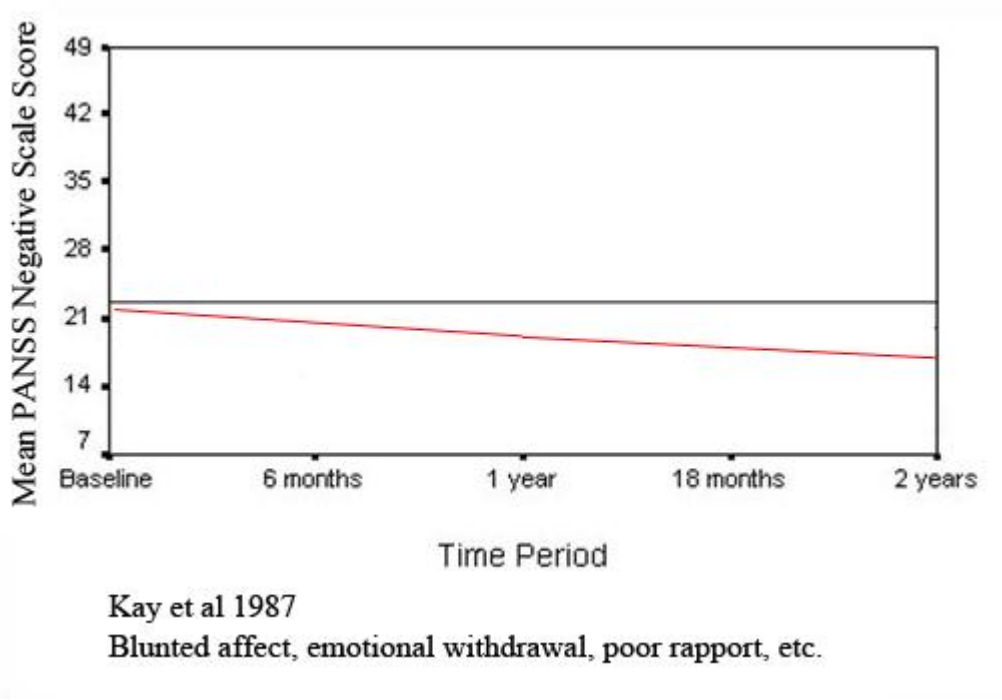

Figure 6.6 PANSS negative scale – EIP clients at baseline, one year and two years – with consistent case base (n=25).

The EIP clients showed a decrease in the mean PANSS Positive Scale score during the first six months in the program from a mean score of 21 to a mean score of 10 (Fig. 6.5). Overall, the change in PANSS Positive Scale scores was statistically significant (sig=.001) taking into account the within subjects effects of the repeated measures. This indicates that the level of positive psychotic symptoms (including, for example, delusions and hallucinations) decreased in the first six months of treatment.

The EIP clients showed virtually no change in the mean PANSS Negative Scale score over the course of the study (Figure 6.6): Baseline (22), one year (21) and two years (20). Negative symptoms are generally found to be more resistant to treatment (Kay *et al.*, 1987).

The General Pathology scale measures symptoms such as somatic concern, anxiety, guilt feelings, mannerisms and posturing, motor retardation, uncooperativeness, disorientation, poor impulse control and preoccupation. The mean PANSS General Pathology scores of the EIP clients declined (and then plateau) during the two year study period with most of the improvement occurring in the first six months (Fig. 6.7): baseline (37.1), six-months (27.2), 12-months (25.0), 18-months (26.1) and two year (26.2). The repeated measure test using consistent cases (n=25) was significant (sig= .023).

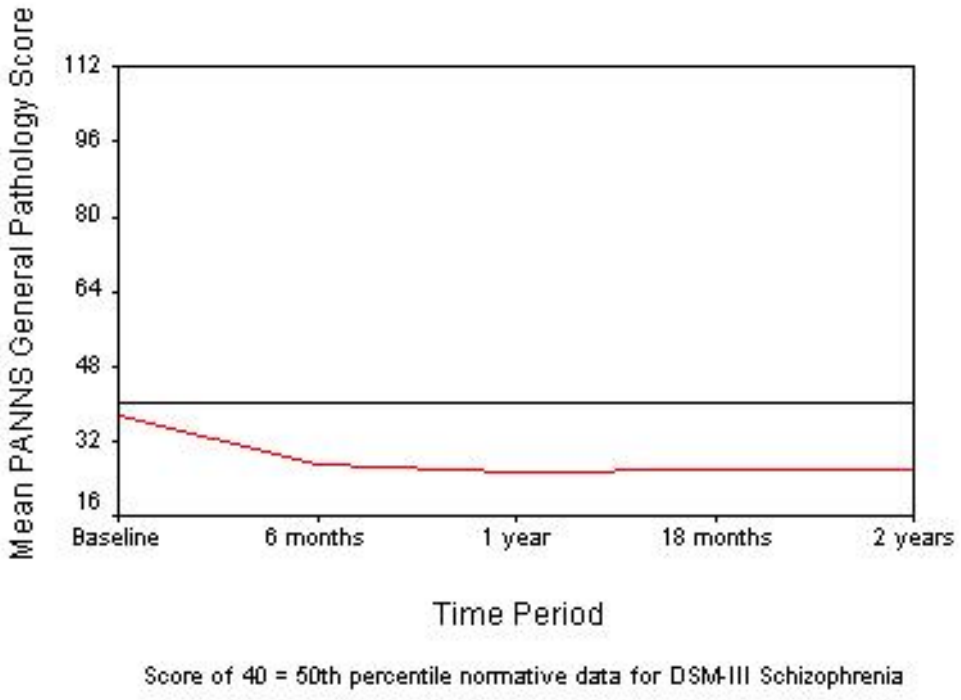

Figure 6.7 PANSS general pathology scale – EIP clients at baseline, one year and two years – with consistent case base (n=25).

The Calgary Depression Scale was developed by Addington et al. (1990) to assess symptoms of major depressive disorders in patients with schizophrenia. The EIP clients demonstrated a low level of depression ranging from a mean of 5.8 at baseline, 2.2 at six months and levelling off at 12 months (1.5), 18 months (1.5) and 24 months (1.8). The repeated measures tests of did show a significant change, using consistent cases, over the five time periods at the sig=.001 level. At baseline, the average CDS score (5.8) indicated a client at risk for co-morbid major depressive disorder. Improvement was demonstrated in the first six months, and improvement held constant over the 12-month, 18-month and 24-month periods. This tool proved to be helpful in monitoring the clinical progress of the EIP clients over the two-year study period.

A significant strength of the scale is that it is tailored to patients with schizophrenia.

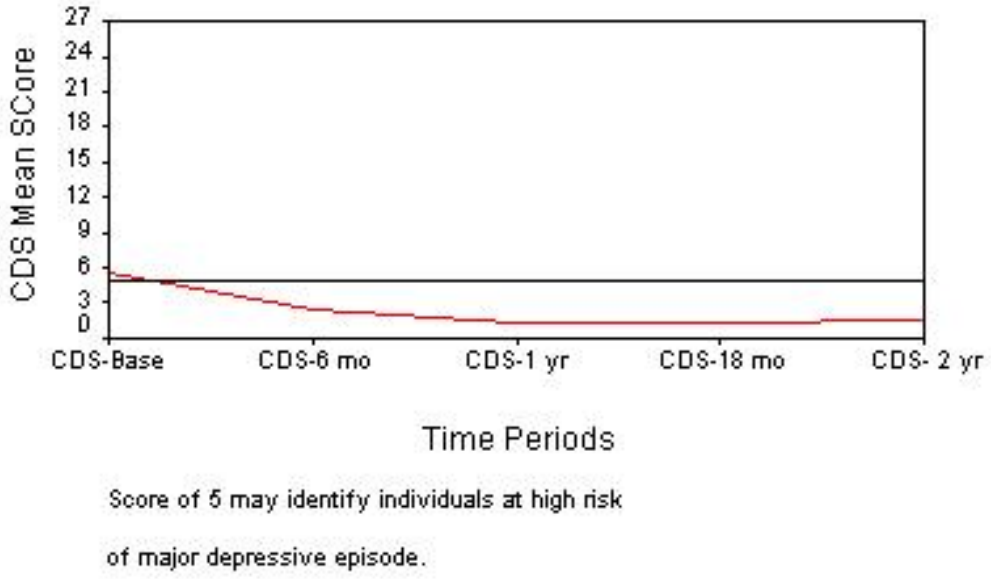

Figure 6.8 Calgary Depression Scale (CDS) for schizophrenia – EIP clients at baseline, one year and two years – with consistent case base (n=23).

The **sixth** Goal/Effect to be explored is "Maximize Individual's Ability to Be Employable" which is at the ultimate level. The measure linked to this Goal/Effect is the Social and Occupational Functioning Assessment Scale (SOFAS).

The purpose of the Social and Occupational Functioning Assessment Scale is to evaluate overall social and occupational functioning (Goldman *et al.*, 1992). The SOFAS mean scores did not change significantly over the three time periods (Figure 6.9). The tests with consistent case base did not show a significant change (sig=.709). The SOFAS showed very limited, if any, evaluation value in this study. Rather than chart progress across the two year

period, this measure can be used to describe the client population in contrast to a normative healthy population. The mean scores at baseline (55.1), one year (58.6) and two year (58.8) can be used to portray a client group that has moderate difficulty in social, occupational and school functioning (e.g. few friends, or conflicts with peers or co-workers). The low end scores of the 95% CI represent an individual with serious impairment in social, occupational or school functioning (e.g. no friends, unable to keep a job). This does speak to the need to maintain a strong program service component in the areas social and occupational functioning to meet the needs of these clients. However, it would appear that two years are too short a period of time to make any comments about change in this functional measure.

Critics of the SOFAS have asserted that it may be more productive to independently measure the domains of social and occupational functioning (Patterson & Lee, 1995). While conceptually appealing, this also proved difficult in the current study. Of the EIP clients, 17.2 % indicated employment at baseline and 18.8% indicated employment at two years, again showing no change in this behaviour-based indicator.

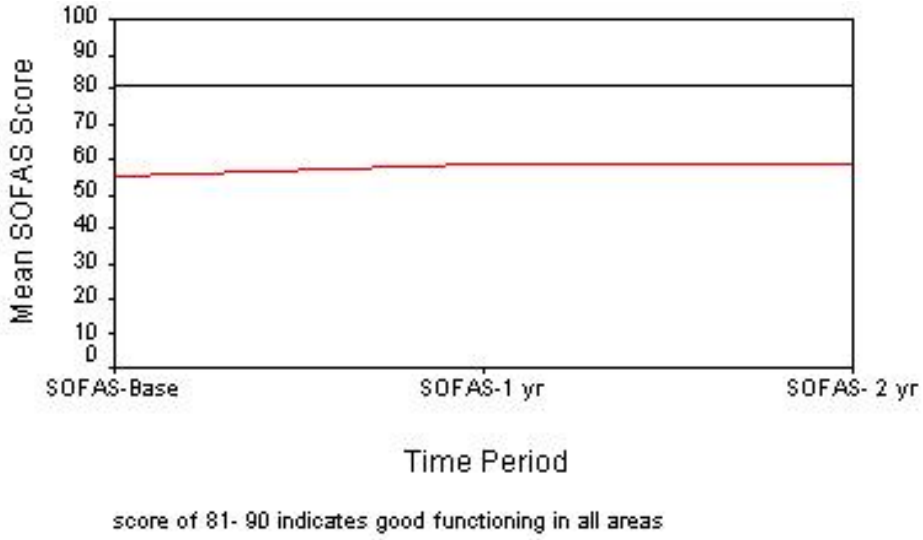

Figure 6.9 Social and Occupational Functioning Assessment Scale (SOFAS) – EIP clients at baseline, one year and two years – with consistent case base (n=23).

6.4 Utilization and cost of in-patient and emergency room services

The **seventh** Goal/Effect to be explored is "Reduce Use of Emergency/Crisis and Acute Care Services" which is at the Intermediate level. The **eighth** Goal/Effect to be explored is "Reduced Illness-Related Utilization of Health Services" which is at the Ultimate level. The measures linked to this Goal/Effect are Emergency Room Utilization, In-patient Admissions, and Total SHR cost (including EIP) (Table 6.6 and Table 6.7).

Table 6.6 Saskatoon Health Region service utilization and characteristics: early intervention and historical clients.				
Item	**Group**	**Mean**	**SD**	**Sig. Equality of Means (equal variances assumed)**
Admissions #	EIP	.93	1.223	
	Historical	1.79	1.762	**.071**
LOS	EIP	18.5	12.358	.384
	Historical	22.9	121.344	
ER # of visits	EIP	1.67	1.642	
	Historical	2.43	2.311	.228
Certified admissions	EIP	.24	.786	
	Historical	.14	.426	.659
Suicide attempts	EIP	.07	.371	
	Historical	.15	.376	.499
No. of justice encounters in the ER	EIP	.1	.310	
	Historical	.36	1.082	.245

Table 6.7 Saskatoon Health Region service costs: early intervention and historical clients.

Item	Group	Mean	SD	Sig. Equality of Means (equal variances assumed)
Inpatient Cost	EIP	$5470	$7876	
	Historical	$12,420	$13,135	**.039**
ER Cost	EIP	$240	$228	
	Historical	$345	$328	.229
Total SHR Cost (incl. EIP)	EIP	$9,068	$7997	.256
	Historical	$12,765	$13,283	

Cost Accounting Assumptions:
Inpatient costs based on 2004 psychiatric unit costs – SCH and RUH.
ER costs based on 2004 emergency room SHR "psychiatric visit" cost.
EIP based on actual 2003 costs.
Meal day (from 2004 SHR annual report) - $21.63.
Housekeeping per patient day - $5.23.
SHR costs provided by Manager, Mental Health Services (with assistance from SHR Financial Services).
EIP cost included: RPN salary and benefits, travel, and office supplies.
(Crown, Neslusan, Russo, Holzer, & Ozminkowski, 2001; Moscarelli, Capri, & Neri, 1991; Rund & Ruud, 1999)

In comparing the Early Intervention Program (EIP) clients and the historical clients, two areas showed a statistically significant difference in the group means: Number of SHR Admissions to Psychiatric Unit (SCH and RUH) and Average SHR Inpatient Cost per Patient.

Number of SHR Admissions to Psychiatric Units (SCH and RUH)

The EIP Clients had a mean of .93 admissions and the historical clients had a mean of 1.79 in the first two years following "first break" psychosis. This is significant only at the .071 level ($p<.10$). Given the severe nature of psychotic disorders both of these admission levels are quite small and help dispel the myth that these patients require significant and repeat admissions. Part of this

difference could be due to an increased focus on utilization management from the mid-90s to the late 90s when the EIP program was launched, causing a higher "admission threshold." The EIP clients had almost one-half the number of admissions, representing an average length of stay of 18 days per admission, which on an individual basis could represent an improved quality of life (avoiding time in hospital). It is becoming more widely accepted that more psychiatric service utilization does not necessarily translate into better outcomes (Huff, 2000).

Average SHR Inpatient Cost per Patient

The mean inpatient cost for EIP clients was $5,470 and the mean inpatient cost for the historical clients was $12,420. This is significant to the .039 level ($p<.05$). This is primarily due to the lower number of admissions for the EIP group (mean of .93) compared to the historical group (mean of 1.79). The length of stay used to calculate the cost was also shorter for the EIP group. Nevertheless, the difference in length of stay between the two groups (18.5 days for the EIP clients and 22.9 days for historical clients), was not statistically significant (sig = .384).

6.5 Psychiatrist satisfaction with early intervention services

The psychiatrists who refer clients to the SHR Early Intervention in Psychosis Program represent a key stakeholder group. Psychiatrist satisfaction with the EIP program was measured for seven domains: 1) Relationship with Family; 2) Relationship with Friends; 3) Symptoms Managed by Medication; 4) Patient's Ability to Function in Daily Life; 5) Overall Treatment Response; 6)

Level of Patient's Function (i.e. Independence) after Treatment, and 7) EIP Follow-up: Attention to Patient Needs. These domains were matched to the corresponding Goals/Effects of the Program Logic Model (*Appendix I*) in order to achieve a comprehensive depiction of the Early Intervention in Psychosis Program, taking into consideration referring psychiatrist satisfaction.

The **first** Goal/Effect examined was "Reduce the Burden and Stress on Self & Family (including significant others)" which is at the Intermediate level. This Goal/Effect was linked to two survey domains: "Relationship with Family" and "Relationship with Friends." In most cases, the program met the psychiatrists' expectations of the effect of the EIP on their patients' relationships with their families (Fig 6.10). For 58% of patients the psychiatrists' expectations were met and for 18% of patients the psychiatrists' expectations were exceeded. The psychiatrists' ratings for this program element were below expectations for only two patients (9%). In most cases, the program met the psychiatrists' expectations of the effect of the EIP on their patients' relationships with friends (Fig. 6.11). For 63% of patients the psychiatrists' expectations were met and for 14% of patients the psychiatrists' expectations were exceeded. The psychiatrists' ratings for this element were below expectations for three patients (14%). Overall, the psychiatrists were satisfied with the effect of the EIP on patients' relationships with their families and friends.

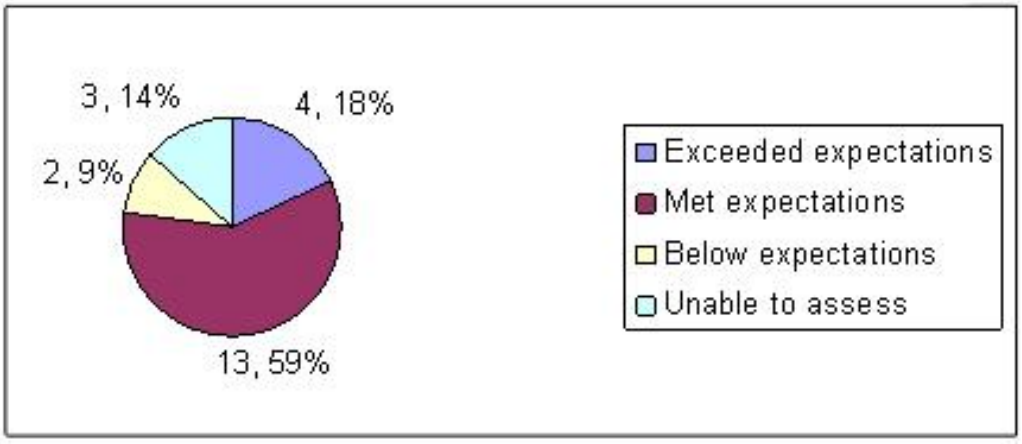

Figure 6.10 Effect of EIP on relationship with family: psychiatrist expectations (patients n=22).

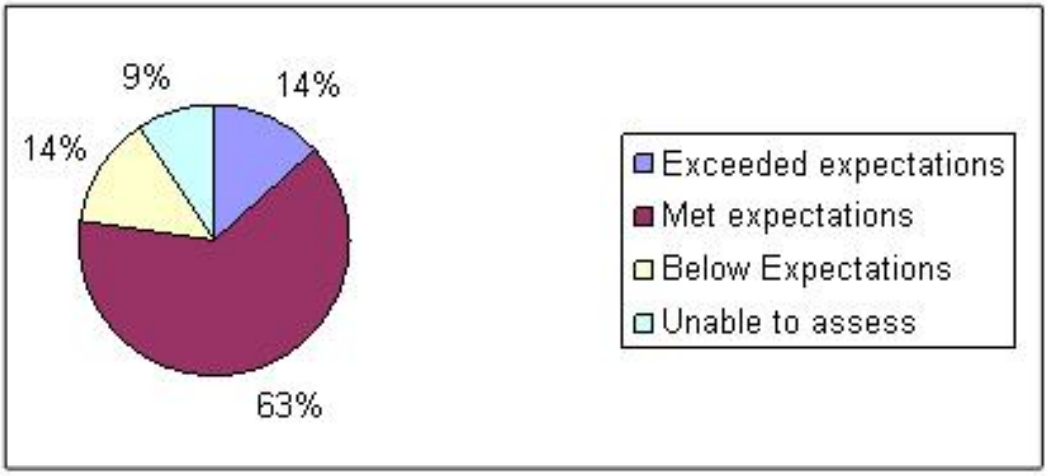

Figure 6.11 Effect of EIP on patient friendships: psychiatrist expectations (patients n=22).

The **second** Goal/Effect to be explored is “Improve Individual’s Ability to Manage Medication” which is at the Immediate level. This Goal/Effect was linked to the survey domain “Extent Patient’s Symptoms Managed by Medication: Psychiatrist Expectations.” As illustrated in Fig. 6.12, the extent

that patient's symptoms were managed by medication exceeded the psychiatrists' expectations for 18% of patients and met the psychiatrists' expectations for 59% of patients. About one-quarter of the time (23%), the extent patient's symptoms were managed by medication was below the psychiatrists' expectations. In the majority of cases, the psychiatrists' expectations for symptom management by medication were achieved.

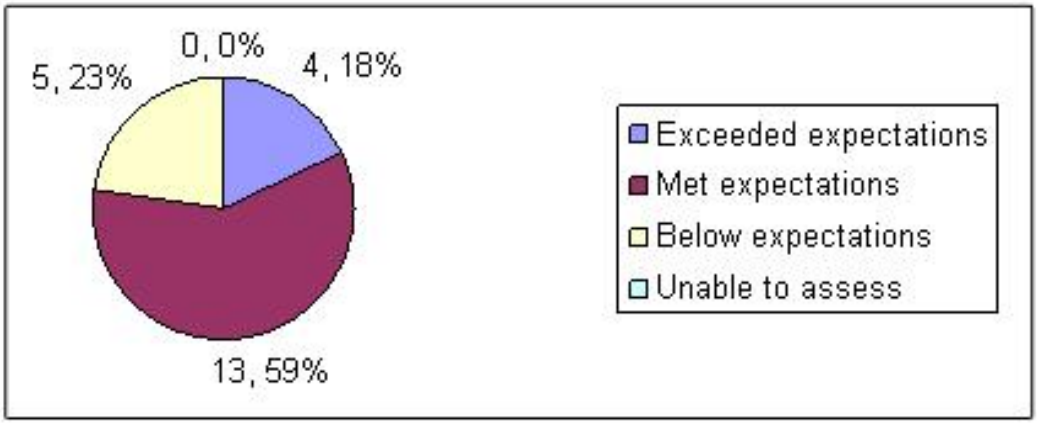

Figure 6.12 Extent patient's symptoms managed by medication: psychiatrist expectations (patients n=22).

The **third** Goal/Effect to be explored is "Reduce the Burden and Stress on Self and Family" which is at the Intermediate level. This Goal/Effect was linked to three survey domains: "EIP Follow-up: Attention to Patient Needs;" "Impact of EIP on Patient's Ability to Function in Daily Life;" and "Level of Patient's Function after Treatment." The psychiatrists gave high ratings to the EIP with respect to Follow-up: Attention to Patient Needs (Fig. 6.13). For 72% of patients, the psychiatrists rated the EIP follow-up "very good" and for 23% of patients the psychiatrists rated the EIP follow-up "good." Follow-up was ranked as "average" for only one patient.

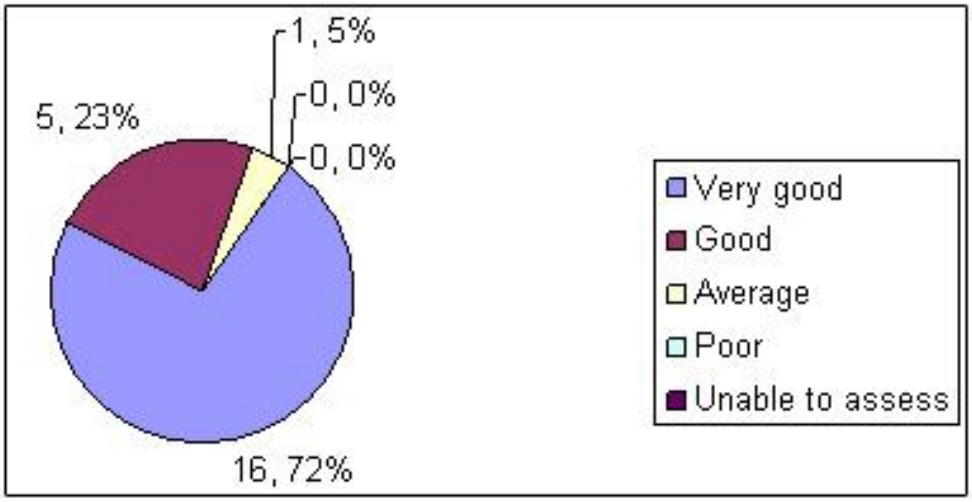

Figure 6.13 Psychiatrist rating of EIP follow-up: attention to patient needs (patients n=22).

Overall, the psychiatrists were satisfied with the impact of the EIP on patient's ability to function in daily life (Fig. 6.14). For 63% of patients the psychiatrists' expectations were met and for 32% of patients the psychiatrists' expectations were exceeded. The psychiatrists' ratings for this element were below expectations for only one patient (5%).

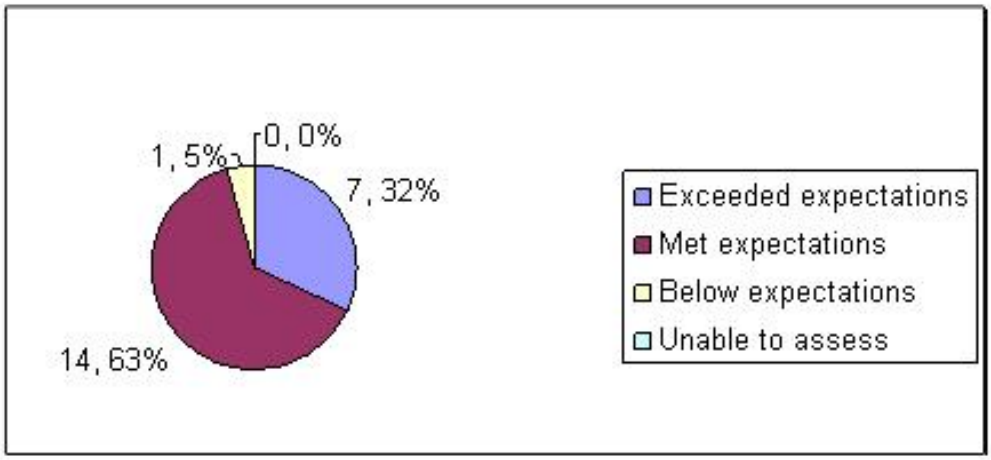

Figure 6.14 Impact of EIP on patient's ability to function in daily life: psychiatrist expectations (patients n=22).

The psychiatrists' ratings of level of patient's function after treatment were mixed (Fig. 6.15): independently (37%), independently with some help (36%), probably not independently (9%) and definitely not independently (9%). In two cases (9%), the psychiatrists felt they did not have enough information to assess this aspect. Overall, independent function was promoted over 75% of the time.

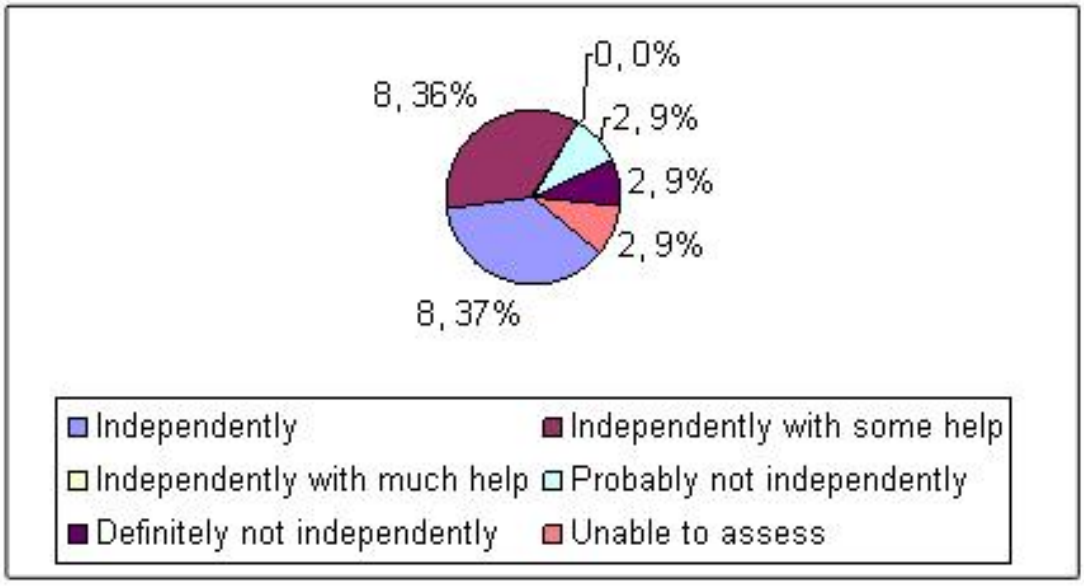

Figure 6.15 Psychiatrist ratings of level of patient's function after treatment (patients n=22).

The **fourth** Goal/Effect to be explored is "Reduce Primary Symptoms of Psychotic Disorder (Duration and Severity)" which is at the Intermediate level. The measure linked to this Goal/Effect is "Overall Treatment Response (including EIP): Psychiatrist Expectations". Overall, the psychiatrists' ratings of treatment response was mixed: exceeded expectations (27%), met expectations (41%) and below expectations (32%) (Fig. 6.16). This may reflect the treatment-

resistant nature of schizophrenia and other psychotic disorders (Chakos, Lieberman, Hoffman, Bradford, & Sheitman, 2001).

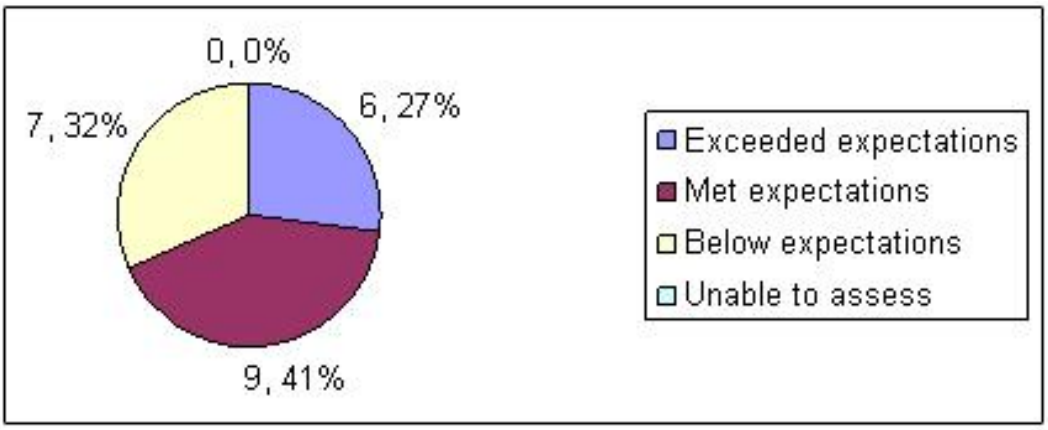

Figure 6.16 Overall treatment response: psychiatrist expectations (patients n=22).

In response to the open-ended comment section, psychiatrists provided constructive feedback about the Early Intervention Program's performance. Thematic content analysis identified two major themes and eight sub-themes: "EIP Program Performance" (service quality, inter-professional team, and patient flow) and "Patient Prognosis and Outcome" (response to medication, employment and education, compliance with treatment, co-morbid substance abuse and social support). Psychiatrists' comments by theme and sub-theme are presented in *Appendix M*.

EIP Program Performance

The **first** major theme to emerge was "EIP Program Performance." Within this major theme, the **first** sub-theme was "Service Quality." The overwhelming majority of feedback from psychiatrists, with respect to "Service Quality" was positive. Early Intervention in Psychosis was described as an

"excellent program" that "made a huge difference." It was stated that the EIP program is "useful and helpful to both patient and psychiatrist." Support provided to patients was called "appropriate," "effective" and "very valuable in the strong recovery of my patient." It was reported that the EIP program was "very helpful in addressing acceptance of illness, compliance with medication, and a healthy lifestyle." It was noted that the program serves families as well as clients. Psychiatrists commented that the EIP provided "good family support" and "seemed to engage family well." Nevertheless, one psychiatrist observed that ""with repeated relapses, the patient deteriorated. EIP could not have an impact despite (its) efforts."

Within the first major theme of "EIP Program Performance," the **second** sub-theme was "Inter-professional Team." Again, the overwhelming majority of feedback from psychiatrists, with respect to "Inter-professional Team" was positive. A number of comments supported the role and contribution of the program's registered psychiatric nurses (RPN). One psychiatrist stated that the RPN "was an excellent source of support and provided excellent education re: lifestyle issues (e.g. not using drugs). The patient related well to (RPN) and respected (his/her) advice." In one instance, the "dedicated, resourceful, responsive community nurse" was called the EIP's most important feature. As well, "having a dedicated, enthusiastic community nurse was the most important."

Continuity of care was seen as an important aspect of the EIP program. For example, when the initial psychiatrist left on sabbatical leave for one year, the EIP nurse provided the important continuity. As well, the consistency of

nurse and psychiatrist was seen as an important feature of the program providing continuity so the patient is not "passed from professional to professional." It was stated that the EIP program "dove-tailed nicely with the McKerracher Program," a psychiatric day program offered by the Health Region. As a result of the EIP, the "therapeutic alliance was much improved."

Within the first major theme of "EIP Program Performance," the **third** (although less prominent) sub-theme was "Patient Flow." In this instance, suggestions for EIP program improvement were made. It was stated that, "Intake is a hindrance because some patients are in hospital. It would be helpful to be able to contact EIP independently to get an earlier, sometimes more informed opinion."

Patient Prognosis and Outcome

The **second** major theme to emerge was "Patient Prognosis and Outcome." Within this major theme, the **first** sub-theme was "Response to Medication." It was noted that the "EIP worked well but the patient had poor response to meds." In another instance, it was reported that the "patient started improving after he was switched to clozapine." Given this limited feedback, it is difficult to assess the program's effect on "Response to Medication."

Within the second major theme of "Patient Prognosis and Outcome," the **second** sub-theme was "Employment and Education." The feedback from psychiatrists in this aspect was very encouraging. One psychiatrist reported that, "After two years of treatment (the patient) was able to complete life skills course, and has part-time work." In another instance, the patient was "able to return to school and repeated Math class successfully. Has motivation to attend

Kelsey program for computer course." Other positive remarks included: "doing fairly well academically", "doing well in work placement" and "presently in school." In one isolated case, the patient "did not want to work which caused added stress."

Within the second major theme of "Patient Prognosis and Outcome," the **third** sub-theme was "Compliance with Treatment." Compliance with treatment was variable. It was noted that some patients "had no insight, refused ongoing contact and became transient." In some cases prognosis is "guarded as patient is non-compliant." It was recognized that other community resources such as a care home provide important support and follow-up to encourage adherence to treatment. In another case, the patient was "a very conscientious person who worked hard on understanding the illness and what he needed to do to succeed."

Within the second major theme of "Patient Prognosis and Outcome," the **fourth** sub-theme was "Co-morbid Substance Abuse." Co-morbid substance abuse was an ongoing challenge in treating this patient group. One psychiatrist noted that his patient "regularly used substances and (received) no regular treatment." In another case it was noted that the "patient had poor insight, and continued use of alcohol and drugs." It was reported that the EIP "worked hard with a very difficult patient with drug use issues in co-morbidity." It was recognized that "dual diagnosis issues were resistant to treatment interventions."

Within the second major theme of "Patient Prognosis and Outcome," the **fifth** sub-theme was "Social Support." The psychiatrists acknowledged that EIP patients face ongoing social support challenges as a result of their psychotic

illness. The importance of improving interpersonal relationship with both family and friends (e.g. “dating”) was referenced. One respondent advised: “Patient does well in Care Home and EIP - not best (for this patient) to live alone.” Another stated that “the program worked very well to help a concerned anxious family become appropriately helpful and better adjusted.” The EIP program was considered a “good support for patients with low social supports.”

Overall, the psychiatrists held a positive perception of the EIP program. It was seen as being an effective program with strong nursing staff. Positive outcomes in areas such as employment and school were recognized. Ongoing challenges, characteristic of this patient group, such as non-compliance to treatment and co-morbid substance abuse were acknowledged.

6.6 Focus groups: thematic analysis

Focus group participants represented key stakeholders of the Early Intervention in Psychosis Program: nursing, psychiatry, psychology and management (*Appendix N*). Content analysis identified major themes, theme-branches and sub-themes (Table 5.9 and *Appendix O*). For reporting of results, the sub-themes were matched to the corresponding quality domain: structure, process, or outcome (Table 5.10 and *Appendix P*).

Table 6.8 Focus group themes, theme-branches and sub-themes		
Theme	**Theme-branch**	**Sub-theme**
Strengths of EIP Philosophy	Improved model of care	Increased family involvement
		Team approach
		Emphasis on education
		Improved treatment compliance
		Reduced stigma
	Improved prognosis	Retarded neurodevelopment deterioration
		Reduced chronicity
Weaknesses of EIP Philosophy	Disease focus	Challenges of diagnosis
Impressions of SHR EIP Program	Successes	Staff skill and commitment
		Reduced hospitalization
		No wait list (quick response)
		Positive image of program
	Challenges	Lack of resources and sustainability
		Staff burnout
		Family conflict
		Service fragmentation and ambiguity
		Team dynamics
		Co-morbidity
		Inconsistent and inappropriate referrals
Organization design and structure	Unclear structure	Lack of integration
	Staffing	Child and adult psychiatrists
		Role of family physicians
		Role of other professions
	Medical affairs	Conflict and turf protection
		Funding models
		Renewed medical leadership
Future directions	Clarify organization structure	Nested program
		Renewed medical leadership
	Intersectoral collaboration (e.g. school programming)	Outreach team
		Role of teachers and counsellors
	Enhanced staffing	Family worker
	Education and communication	Medical education
		Website (family, patients, professionals)
	Research and evaluation	Assessment staff
		Minimum data set

Table 6.9 Focus group sub-themes by quality domain: structure, process and outcome.	
Quality Dimension	**Sub-theme**
Structure	Team approach
	Staff skill and commitment
	Lack of resources and sustainability
	Staff burnout
	Service fragmentation
	Team dynamics
	Lack of integration
	Medical leadership
	Child and adult psychiatrists
	Role of family physicians
	Funding models
	Nested program
	Outreach team
	Role of teachers and counsellors
	Family worker
	Medical education
	Website (family, patients, professionals)
	Assessment staff
	Minimum data set
Process	Increased family involvement
	Emphasis on education
	Challenges of diagnosis
	Family conflict
	Inconsistent referrals
	Conflict and turf protection
	Increased communication
	No wait list (quick referral)
	Co-morbidity
Outcome	Improved treatment compliance
	Reduced stigma
	Retarded neurodevelopment deterioration
	Reduced chronicity

Within the **structure** quality domain, the sub-themes revolved around staffing, funding and resources, and system integration. The **first** sub-theme related to staffing was “team approach.” The team approach was viewed as a key strength of the EIP program. A focus group participant commented that “the

team approach is what is critical and necessary." The **second** sub-theme was "staff skill and commitment." Staff skill and commitment was viewed as a key success factor of the EIP program. It was stated that the consultant psychiatrists were held in "very high regard" and the program's nurses were very "creative." It was noted, however, that the "most dedicated people have never been thanked properly." The **third** sub-theme was "staff burn-out." This sub-theme elicited considerable commentary in the focus group interviews. Some of the stress and burn-out appeared to be a result of heavy nursing workloads (caseloads of up to 40 EIP and rehab patients per nurse). It was noted that "working with the EIP program (the nurses) had to wear a lot of hats." Some of the stress came from the challenges commonly associated with this complex client group (e.g. co-morbid substance abuse, non-adherence to treatment). It was stated that nursing staff were "overwhelmed and the challenge was horrendous." Lack of resources was also a contributor to staff burn-out. It was acknowledged that "if you don't have the appropriate funding, you burn out." It was noted that the EIP psychiatrists were overloaded as well. After the Health Region started to rotate the nurses in and out of the EIP program (starting in 2005), it was observed that "coming back to it after one year, (staff) did see improvements." The **fourth** sub-theme was "team dynamics." Team dynamics were seen as an important challenge for the EIP program. It was noted that at times "there seemed to be no communication" and there was "bickering" amongst team members. There was conflict between adult and child psychiatrists, and some "animosity" existed between the program and its

referring psychiatrists. It was concluded that “it was not a very (well) defined team, so it sort of fell apart.”

The next group of sub-themes in the structure domain revolved around medical human resources. The **fifth** sub-theme was “medical leadership.” The departure of the two consultant psychiatrists in 2005 led to a vacuum in medical leadership. A focus group participant observed that when the consultants left, “the program sort of dissolved.” The **sixth** sub-theme was “child and adult psychiatrists.” Focus group participants recognized the need for both a child and an adult psychiatrist to support the EIP program (the original two consultants were both adult psychiatrists). The shortage of child psychiatrists in the Saskatoon Health Region was acknowledged, referencing a referral wait time of “six to twelve months.” Interest was expressed in seeing the emergence of a local specialist in psychosis similar to “other specializations such as geriatric psychiatry.” The **seventh** sub-theme was “role of family physicians.” In general, there was a perception of “lack of support from family physicians.” The program made considerable effort to educate family physicians about the program. The program held “many supper meetings…about four of them in a span of two years, and we desperately tried to educate the GPs.” There was a sense that “GPs don’t see many psychotic patients, they are more interested if you talk about anxiety or depression.” The **eighth** sub-theme was “outreach team.” The focus group discussions identified opportunities for psychosis prevention by means of inter-sectoral collaboration with the school systems. It was stated that “to find these kids, you need a coalition with the schools.” The schools were seen as the best place to identify young people with psychosis.

The operation of a strong outreach team was identified as an important future direction for the EIP program. Rather than spread this role across the EIP team, it was suggested that "this needs to be assigned to someone, and can't be left to everyone." Another inter-sectoral opportunity was reflected in the **ninth** sub-theme "role of teachers and counsellors." It was acknowledged that early intervention should start when children are as young as twelve to thirteen years old. Further, it was recognized that "a lot of information (could be distributed) through school guidance counsellors." The **tenth** sub-theme recognized the need for a "family worker" to provide specialized support to EIP families. It was viewed that the workloads of the mental health nurses was too heavy to continue this role. The **eleventh** sub-theme was "medical education." Educating the medical community was seen as an important future direction for the EIP program. The need for ongoing training for family physicians and psychiatrists was emphasized. New methods need to be sought because past attempts (e.g. Psychiatry Grand Rounds) were not successful. The final sub-theme identified the need for "assessment staff" to assist with data collection for research and evaluation activities. It was acknowledged that "the documentation was very labour intensive."

Within the **structure** quality domain, the second cluster of sub-themes revolved around resources, sustainability and funding. The **first** sub-theme was "lack of resources and sustainability." This was one of the most prominent sub-themes in the focus group discussions. The observation was made that "we started on a shoe string and if we didn't operate on that we might never have started up." It was stated that the resources the program had "were quite

minimal." This lack of funding contributed to the level of staff stress. It was noted that "due to the lack of resources the RPNs were stretched too thin." As well, it was suggested that the EIP program needed a designated location, like the clozapine clinic. The funding difficulties led to doubts about the program's viability. It was emphasized that the program staff "brain-stormed everything possible to keep this program viable." One participant expressed concern for the future: "I would hope to see it continue." The **second** sub-theme was physician "funding models." It was acknowledged that physician payment methods impact the delivery of care. Fee-for-service payment of community psychiatrists was seen to limit their time available for case conferences and other EIP team involvements.

Within the **structure** quality domain, the third cluster of sub-themes revolved around system integration. The **first** sub-theme was "service fragmentation." Within the EIP service model "nothing seemed to be unified." Ambiguity in services roles existed. At times "there seemed to be no communication (between mental health services)". The **second** related sub-theme was "lack of integration." It was stated that "the (community) psychiatrists were not well integrated and they are still not well integrated." There was lack of clarity around the program's organizational structure. One participant pondered: "I would be curious to know where that is right now." It was recognized that for the EIP program to stay viable there is a need to integrate this program with other services because the EIP can no longer "hang on by itself." The **third** sub-theme was "nested program." It was recognized that "with low incidence…it means you cannot devote a lot of manpower for this disorder." The SHR Early

Intervention in Psychosis program has developed as a separate 'nested' program within mental health rehabilitation. Another suggestion was made to "integrate the EIP program with the rest of long-term psychosis program from orientation to follow-up." It was acknowledged that larger cities and health regions have different options:

> "Calgary has about a million inhabitants, so they have the numbers in terms of new cases, we don't. So that is the whole issue. We can't build up a whole program for a few cases. It (the program) has to be part-time, it cannot be full-time."

Within the **process** quality domain, the sub-themes revolved around family matters, education and communication, professional conflict and turf protection, inconsistent and inappropriate referrals, and challenges of diagnosis. The **first** sub-theme related to family matters was "increased family involvement." Family involvement was seen as one of the main strengths of the EIP approach. One participant commented: "The more families understand and know and appreciate what their child is going through, the more supportive they can be and the more involved they can be." With respect to the Saskatoon EIP program, it was observed that "the families were 'on board', they could work with the individual for compliance." Nevertheless, the level of family programming was minimal and it was observed that "the family piece was thin." The **second** sub-theme related to family matters was "family conflict." While family involvement was recognized as an important strength of the program, it brought added challenges and conflicts. It was noted that there was "quite a bit of friction in a number of cases between the family members and the patient." A staff member identified the tension created from balancing the needs of the

patient and family: "If we associated with the families too much, well, the clients felt abandoned and if we spend too much focus on the clients, the parents felt left out." The **third** sub-theme was "emphasis on education and communication." "Educating people and helping them manage their illness" was identified as another key focus and strength of the program. This included "a six-session family group which was strictly educational." The **fourth** sub-theme was "professional conflict and turf protection." Medical turf protection was called a "big barrier" to the success of the EIP program. Concerns were expressed about "medical politics" and concerns about "stepping on toes." It was stated that "a lot of doctors did not buy into that basic philosophy of early intervention." The **fifth** sub-theme was "inconsistent and inappropriate referrals." Considerable discussion in the focus groups revolved around the high level of inconsistent and inappropriate referrals to the EIP program. Because the EIP program never had a waiting list, it was perceived that "it ended up being a dumping ground" for patients who did not meet the early psychosis criteria. When inappropriate referrals were received it created conflict of the EIP team because they were forced to "argue this isn't appropriate." For an unexplained reason, referrals appeared to come in waves: "We may get like 6 or 7 referrals and then for 3 to 4 months there were no referrals, and we could never really assess why the gap." There was a perception that access to the program was limited, and there was not mechanism of access during the prodromal phase. It was suspected that "there are more people out there with Early Psychosis that the physicians are not sending to us." It was noted that the program received about "eighteen to twenty-two referrals per year" while an annual incidence rate

of 1 to 10,000 population would predict about 28t to 30 new referrals per year. The **sixth** sub-theme was “challenges of diagnosis.” Issues around diagnosis were identified as an important challenge for the EIP program and its psychiatrists. It was recognized that “not all early psychoses will evolve into schizophrenia, some will evolve into bipolar or psychosis NOS.” It was acknowledged that this is “heavy material to deliver to a family” and there is “reluctance to give the diagnosis” because there is a “need to observe the evolution and treat the progression.” It was recognized that the psychiatrists don’t want to “jump to a diagnosis” out of “fear of labelling.” It was acknowledged that families find this delay in diagnosis frustrating. It was noted that other EIP programs are “pushing away the emphasis on this issue (diagnosis), focusing the emphasis on (providing) the best treatment in the world.” In other words, the focus is treatment and symptom control rather than obtaining an early definitive diagnosis. The **seventh** sub-theme was “no wait list (quick referral).” An important success of the EIP program was identified as not have a waiting list and having the ability to “tackle things as quickly as possible.” One staff member summarized: “EIP would get involved ASAP instead of (the client) being put on a waiting list so people can start to deal with their illness.” The **eighth** sub-theme was “co-morbidity.” Co-morbid substance abuse was identified as one of the greatest barriers to effective treatment. In some instances the clients “were self-medicating, so they used marijuana or crystal meth.” In other cases the psychosis “looked clearly drug induced.” Clients with drug-induced psychosis did not meet the initial criteria for admission to the EIP program. In response, one focus group participant queried: “Should people with

drug-induced psychosis be part of the program?" Given the high level of co-morbid substance abuse, it was not that "the integration of addictions services and early intervention is critical." Co-morbidity appeared to negatively impact outcome: "when it came to the client being dual, the impact was more guarded, the prognosis was more guarded, and the outcomes were not as favourable." It was noted that dual diagnosis did not only mean substance abuse, but could also include ADHD or dissociative conditions. The **ninth** sub-theme was "website communications for patient, family and professional." On a practical level, the need for website communication was identified. The role of the website could be to educate family physicians, provide access and referral information, and offer general information for the public.

Within the **outcome** quality domain, the sub-themes revolved around improved treatment compliance, reduced stigma, slowing neurodevelopment deterioration, and reduced chronicity. The **first** sub-theme related to the outcome domain was "improved treatment compliance." Improved treatment compliance was seen as an important strength of the EIP program. It was noted that EIP staff develop "positive rapport so that they (the clients) stay in treatment." It was helpful that "the families were 'on board', and they could work with the individual for compliance." The **second** sub-theme was "reduced stigma." It was acknowledged that the EIP program plays an important role "telling people that they have schizophrenia and it's nothing to be ashamed of, that it is an illness." This in turn would provide "the words and understanding so it is not so scary." One staff member commented: "I found that working with families, if they could understand what was going on, they didn't get so affected

by the preconceived myths." Another means to address stigma was "educating the general public about what (the clients) have and how it works." The **third** sub-theme was "retarded neurodevelopment deterioration." There was consensus within the focus groups that Early Intervention "retards neurodevelopmental deterioration." It was stressed that psychosis should be treated like a head injury: "If we look at what we know about brain injured people, the first year is critical." It was stated that a key issue is the "degradation of the untreated psychosis." The **fourth** sub-theme related to the outcome domain was "reduced chronicity." It was noted that "one thing that was good to see was that people in early intervention did not go on into long term rehab." Yet, despite the efforts of the EIP "some chronicity, some behavioural components were developing." The **fifth** sub-theme related to the outcome domain was "reduced hospitalization." It was observed that some EIP clients had "never been hospitalized" and that in other cases "the stay in hospital has certainly been shortened." The **sixth** sub-theme was "positive image of the program." Early in its development the EIP achieved a strong positive image amongst program care providers and other mental health staff. Overall, focus group participants were "very impressed with the program and what outcomes it could have with individuals." Initially, EIP staff was "very excited" because "it was something that had never been focused on before." It was indicated that the program was launched with some "grandiosity" and there were great expectations of the model. It would appear that not all of these expectations were met as the program confronted funding, staffing and other challenges.

7.0 DISCUSSION OF RESULTS

7.1 Study results: relevance to study questions

To facilitate discussion, results were aligned with the applicable study question and are presented in a quality domain matrix (Table 7.1).

Table 7.1 Study questions: elements of structure and process that contribute to (or detract from) the effective provision of early intervention in psychosis services, and outcome of early intervention programming.

Quality Domain	Contributors	Detractors
Q1 - Structure	Inter-professional staff	Staff burn-out
	Nested program	
Q2 – Process	School programming	Co-morbid substance abuse
Q3 – Outcome	Reduced hospitalization and cost	

7.2 Structure

The following discussion section addresses study question #1:

Q1: What elements of structure contribute to (or detract from) the effective provision of early intervention in psychosis services?

7.2.1 Elements of structure - contributors

7.2.1.1 Inter-professional team

The SHR Early Intervention in Psychosis Program would benefit from a more sustained and diverse inter-professional team with defined medical leadership. This element acts as a contributor to the effective provision of early intervention services. Since the program's inception, the inter-professional team environment has been an asset of the program. Nevertheless, there is a need for ongoing involvement in the areas of neuro-psychology, family work and child psychiatry. To ensure the ongoing stability of the program, it is also important to identify a medical director.

Neuropsychological impairment has been documented in schizophrenia and other psychotic disorders (Heinrichs & Zakzanis, 1998). Riley et al. (2000) found that even at first presentation of psychotic symptoms, schizophrenic patients show "significant impairment on tasks of executive function, verbal learning, delayed recall from non-verbal memory, and psychomotor speed." These functions showed impairment against a "background of generalised, but non-significant, underperformance on all neuropsychological variables, including attention, verbal and non-verbal working memory, recall from verbal and non-verbal memory, and spatial skills." This evidence supports the sustained involvement of a neuropsychologist on the Early Intervention team.

The EIP program would benefit from further clarification of family programming and the required human resources to deliver these services. The program originally offered family services delivered directly by the program's

mental health nurses and later through a working relationship with Child and Youth Services. Research shows that families play a major role in recovery from a first episode of psychosis (J. Addington, Collins, McCleery, & Addington, 2005; J. Addington *et al.*, 2000). Addington et al (2005) promoted the role of family work in early psychosis highlighting that "the development of services for families has to be an integral part of any comprehensive program." This approach is supported by a recent study completed by Hoagwood (2005). In this systematic review, Hoagwood found that rigorous studies demonstrate "unequivocal improvements" in essential outcomes, such as retention in services, knowledge about mental health issues, self-efficacy, and improved family interactions. Although, it was further concluded that too few experimental studies exist to conclude decisively that family-based services improve youth clinical outcomes.

Given the young age of onset of first psychosis, the involvement of a child psychiatrist is an important ingredient in the ongoing success of the program. It is recognized that mental health services are not always as "youth-friendly" as they should be. Young people surveyed by RETHINK, a mental health advocacy group in the UK, found mental health services stigmatizing, therapeutically pessimistic, and youth insensitive (RETHINK, 2007). Regular involvement of a child psychiatrist in the Early Intervention program would help foster a stronger youth culture and age-appropriate strategies. However, it would also necessitate a transition plan as the client approaches adulthood and referral to an adult psychiatrist.

With the departure of the two original consultant psychiatrists (one who served as Medical Director for the Early Intervention Program), there was a void of medical leadership within the program. It is important that the Health Region stabilize this leadership vacuum. In a report on the role of the psychiatrist as medical director, Ranz et al (2000) suggest that, generally, the term "medical director" is used to describe psychiatrists functioning in an often ill-defined relationship with a non-medical administrator. They note there can be “considerable ambiguity” in the medical director's role, especially regarding authority and relationships with other administrators. In addition to recruitment of a medical (clinical) director, the role needs to be clarified in relationship to the Department of Psychiatry and the Health Region management structures. Alternatively, clinical leadership could be provided by an advanced practice nurse or clinical nurse specialist, psychologist, social worker or occupational therapist.

In addition to an optimal “mix” of professionals on the EIP team, efforts can be made to develop and promote competencies in teamwork. Liberman and team (2000) studied the competencies required for effective multidisciplinary teamwork in psychiatric rehabilitation. They found that several critical elements of a multidisciplinary team will facilitate teamwork (Liberman, Hilty, Drake, & Tsang, 2001):

- the team must bring together people who possess the requisite expertise;
- the team must integrate the different areas of expertise at the level of service delivery;

- mechanisms for accountability for achieving favourable outcomes for clients must be established;
- versatility among team members should be cultivated, so that the team encompasses flexible levels of intervention to meet the individualized needs of clients.

7.2.1.2 "Nested" program

One theme that emerged from the focus group discussions was the concept of the Early Intervention Program being a "nested" program within SHR Rehabilitation and Adult Mental Health Services. It has been found that early intervention services, configured on locally determined needs, are generally more realistic, appropriate and effective (Singh and Joyce, 2003). A review of academic and popular literature found the term "nested" used in three primary contexts. First, in computer programming, a nested function (or nested procedure) is a function which is encapsulated within another function (Dale & Lewis, 2004). The nesting is theoretically possible to any level of depth, although only a few levels are normally used in practice (Dale & Lewis, 2004). Second, in post-secondary education, a "nested" program is one that has associated lower level programs "nested" within it; for example, an Advanced Diploma may include "nested" Diploma and Certificate programs (Queensland University of Technology, 2007). So, for example, a student can use their achievements in the Diploma and Certificate programs toward the Advanced Diploma in a progressive manner. Third, multivariate statistical analysis uses the concept of "nested" data (Hair, Black, Babin, Anderson & Tatham, 2005). References in the literature to a "nested" program in the area of organizational

design in a health care context were not found, so this appears to be an original use of this term.

The SHR Early Intervention in Psychosis program operated as a “nested” program situated with Mental Health and Addiction Services, Saskatoon Health Region (Fig. 7.1).

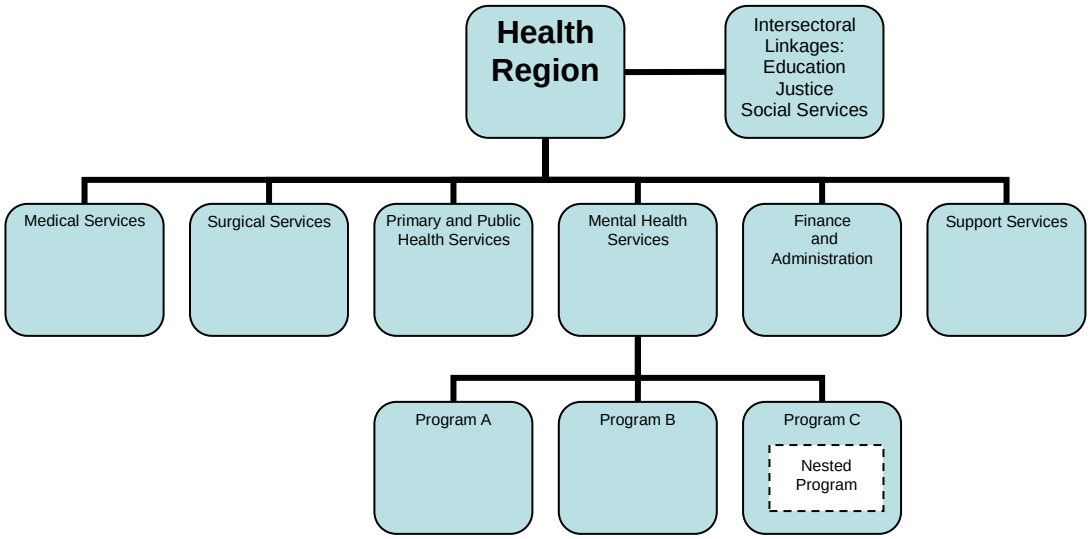

Figure 7.1 “Nested” program model – health region.

This organizational model offers opportunities for coordination and integration, and is cost-effective. Organizational theory suggests that this model will support intra-organizational coordination including: 1) service units work in closer harmony with each; 2) service units know the share of a common task it must share; and 3) work schedules are integrated (Longest, Srakich, Darr, & Rakich, 2000). Within the “nested” model there is less risk that the Early Intervention Program, an out-patient and home-based service, will become isolated from the inpatient units and other out-patient programs. This would help

reduce difficulties with admission and discharge planning, leading to improved continuity of care. In the “nested” model, long-term follow-up may be improved with fewer patients lost to follow-up. Similar to the post-secondary education model of “nesting”, when a client “graduates” from the Early Intervention Program they can use that “achievement” toward participation in the Rehabilitation Program in a “progressive manner.” An added benefit of the “nested” model includes the enhanced intra-program communication with corollary programs within the overall Mental Health and Addictions Program. For example, it facilitates ongoing dialogue with Children and Youth Mental Health Services and Addictions Services to seek joint program-wide solutions to the challenges faced by Early Intervention in Psychosis clients.

A program model, such as the “nested” program, operates in a modified matrix management model with respect to professional standards (e.g. Saskatoon Health Region maintains a professional leadership function to support the organization’s Chief Nursing Officer). One particular characteristic of matrix organizations is the dual lines of responsibility and accountability (Fetter & Freeman, 1986). Matrix management presents some risk of diminution of professional practice standards because lines of authority can become blurred. The EIP program would benefit from increased focus on the important role of mental health nursing and nursing standards within the program. Most of the outcomes assessed in this study had a foundation in psychiatry or psychology. There is a need to expand this approach to include clinical indicators that measure mental health nursing standards of practice (O'Brien, Boddy, Hardy, & O'Brien, 2004). It would benefit the EIP program to consider a

means to monitor mental health nursing practice in a more systematic manner. While feedback from the focus groups and psychiatrist surveys commended the quality of nursing care in the EIP program, this would support and complement their ongoing efforts.

The “nested” model is a cost-effective option that provides the needed part-time managerial and clinical staffing. In the case of the Saskatoon program, the manager was also responsible for other Mental Health Rehabilitation and Adult Services. As well, the EIP nurses maintained clients from the long-term rehabilitation program to accommodate fluctuations in the EIP intake. A full-time manager, medical director and multiple psychiatric nursing positions are not required to support the “nested” program, thus making it a very cost-effective solution. The “nested” program can also be supported by part-time psychology, adult and child psychiatry, and other social and family support services. As a result, this model is highly applicable to small mental health services found in mid-sized urban locations. The “nested” program concept is valuable for health regions with mid-sized urban populations (<500,000). Due to the low incidence of psychosis, these regions may not have sufficient client numbers to develop a larger stand-alone program.

7.2.2 Elements of structure - detractor

7.2.2.1 Staff burn-out

Burn-out is a syndrome of emotional exhaustion that occurs frequently among individuals who do human service work (Maslach & Jackson, 1981). The SHR mental health nurses experienced a high degree of work stress that at

times approached burn-out. This likely resulted from a number of factors including heavy caseload (about 35-40 clients on average), intense working environment (i.e. volatility of the client group), relatively low level of supervision, and heavy documentation demands. There has been concern expressed in the literature that community care models, especially those providing intensive care, cannot be sustained over long periods of time because of their stressful impact on staff (Prosser, Johnson, Kuipers, Szmukler, Bebbington, & Thornicroft, 1996). Burn-out has been reported among both hospital and community staff, with higher levels in community mental health workers (Prosser *et al.*, 1996). Depersonalization, reduced job satisfaction and increased sick leave have been associated with burn-out (Onyett, Pillinger, & Muijen, 1997). Community work may be inherently more stressful than hospital work, or may be stressful because of inadequate resources (Prosser *et al.*, 1996). SHR early intervention program was launched without incremental resources, so this likely played a role in creating a more stressful work environment.

In 2006, the SHR Early Intervention Program started a system of "rotating" the mental health nurses in and out of the program. This staff rotation approach is supported in the literature (Prosser *et al.*, 1996). This high level of staff turnover, rather than increasing burn-out, may lead to a greater sense of personal accomplishment among team members (Prosser *et al.*, 1996). However, high staff turnover can have implications for continuity of care for patients (Prosser *et al.*, 1996).

Some of the work stress reported by SHR early intervention mental health nurses may be attributable to high caseload (35-40 clients/nurse). With other

early intervention services, a lower staff to client ratio is observed. For example, the United Kingdom government's early intervention implementation guidelines recommend the appointment of a case manager with a staff to client ratio of 1:12 (Pelosi & Birchwood, 2003). Caseload size and frequency of contact are discussed elsewhere in the literature. The expectations of case managers concerning the direct provision of services, the outreach mode of service delivery, involvement with client crises, highly individualized service, the breadth of life domains to be attended to, and the liaison role with community resources inevitably requires a high staff to client ratio (Rapp, 1998). Assertive Community Treatment (ACT) programs recommend a staff to client ratio of one to ten (Witheridge, 1991). The strengths model of case management suggests caseload sizes of up to one to twenty (Macias, Kinney, Farley, Jackson, & Vos, 1994). Both approaches suggest that it is important to tailor caseload size to the needs presented by clients and the outcomes sought by the intervention (Witheridge 1991). According to Rapp (1998), positive client outcomes are compromised with caseloads exceeding twenty to one. However, some ambiguity still surrounds the impact of caseload on staff burn-out. Onyett and colleagues (1997) found that caseload size, composition and the frequency with which service users were seen were not associated with job satisfaction or burn-out.

Staff stress and burnout could impact the sustainability of the Early Intervention in Psychosis program. Concerns have been expressed in the literature that staff burnout may make community mental health care difficult to sustain (Prosser *et al.*, 1996). A British research team (Prosser *et al.*, 1996)

compared stress and job satisfaction between community and hospital-based staff. The General Health Questionnaire (GHQ-12), the Maslach Burnout Inventory and a job satisfaction measure were used to study Inner London staff (n=160). Results showed that community staff scored significantly higher on the GHQ-12 and the "emotional exhaustion" component of the Maslach Burnout Inventory than hospital-based in-patient, day care or out-patient staff. Job satisfaction did not vary significantly between settings. The study team suggested that community work may be inherently more stressful than hospital work, or may be stressful because of inadequate resources, training or supervision.

Staff burnout can detract from the effective provision of early intervention services, and can place staff under undue emotional and physical stress. Given this evidence, it would be valuable for the Saskatoon Health Region to reassess its community mental health caseload and workload parameters, especially for high intensity clients such as those seen in the early intervention in psychosis program.

7.3 Process

The following section addresses study question #2:

Q2: What elements of process contribute to (or detract from) the effective provision of early intervention in psychosis services?

7.3.1 Elements of process - contributors

7.3.1.1 School outreach and programming

Effective early intervention programming requires early detection strategies for untreated first-episode psychosis (Larsen *et al.*, 2001). A prime location for these initiatives is within the school systems. Several groups have researched the feasibility of designing screening procedures to identify youth at risk of developing a psychotic illness (Phillips, Yung and McGorry, 2000), although these methods raise a number of ethical concerns related to "false positives" and the risk of premature labelling, stigma and treatment (Yung & McGorry, 1997). Consensus seems to rest with school programming that deals with early detection rather than prodromal screening. While other successful models of school-based screening in the area of children's mental health exist (Casat, Norton, & Boyle Whitesel, 1999), it was in less contentious areas such as disruptive behavioural problems with a lower-risk of harm due to a false-positive score.

A Norwegian team led by Johannessen (2001) describes a school early detection programming:

> Every high school in the county was visited twice each semester by the Detection Team (CT) at times set by the county school administration and school principals. Programs were designed for counsellors, teachers, and pupils. For example, illustrative cases of early psychosis were discussed with teachers and counsellors. Counsellors received further training and rated videos of early psychosis cases. Everyone, including students, was informed about what signs to watch for and given information about referring to the DT. A large educational kit was sent to each school. (p. 41)

The campaign to educate school children about the early signs of psychosis was coordinated with public education Johannessen *et al.,* 2001):

> A full-page ad appeared in the main county newspaper announcing to pupils that they would be receiving a brochure on 'the school of life' in a week's time at school. On that day, a full-page newspaper ad carried a picture of the principal of the most prestigious secondary school in the region, with his text discussing the importance of early detection and intervention. That day, all pupils in the county received the brochure in question. It detailed the warning signs of psychosis and offered the TIPS number for advice, more information, or help. Still photos of the brochure appeared during the next week in the cinemas and in the newspapers. (p. 42)

The Johannessen team (2001, p. 43) found that as a result of school programming, coupled with education to the general public and professionals that "DUP was significantly reduced from 114 weeks to 26 weeks (mean) and from 26 weeks to 5 weeks (median) in the early detected sample, a difference of about one and a half years."

Nova Scotia has focused on school programming by means of a workshop called "Something is not quite right: Early detection of serious mental illness, including psychosis" (Lines, 2001) This half-day workshop program is designed for junior and senior high school staff (teaching and non-teaching) and university student services personnel. In its first two years of operation (1999-2001), over two-hundred staff members participated from several school boards and universities in Nova Scotia (Lines, 2001). Sessions are case-based, highly interactive, multimedia presentations. Following the workshop, interested participants are encouraged to attend the Early Psychosis Mentorship Program to obtain more in-depth information on specific aspects of assessment and treatment of first-episode psychosis (Lines, 2001).

The SHR Early Intervention program has offered limited services in the school on an ad hoc basis. The program would benefit from re-developing this strategy into a more concrete and targeted approach. Overall, school programming is an important contributor to effective early intervention programming.

7.3.2 Elements of process – detractors

7.3.2.1 Co-morbid substance abuse

Co-morbid substance abuse was identified as one of the greatest barriers to effective treatment in the EIP program. Persistent and untreated substance abuse detracts from the effective provision of EIP services. Literature confirms that substance abuse is one of the most common problems in the treatment of early psychosis. Co-morbid substance abuse in schizophrenia is a major concern in view of the high frequency of substance abuse among these patients (Buckley, 1998). It is recognized that dual diagnosis patients are "notoriously difficult to treat" (Buckley, 1998 p. 26). Studies show that psychotic patients with co-morbid substance abuse have a greater utilization and cost of health services (Bartels, Teague, Drake, Clark, Bush, & Noordsy, 1993; Kivlahan *et al.*, 1991). Two main theories have been introduced to explain the increased rate of substance use disorder in these patients (Edwards and McGorry, 2002). These theories include the idea that substance use could "trigger" psychotic symptoms in vulnerable individuals or that these substances are used to "self-medicate" symptoms of psychosis (Edwards and McGorry, 2002). According to Edwards

and McGorry (2002), it can be difficult to determine whether substance abuse is an effect of the illness, whether it has contributed to onset of psychosis, or both.

Difficulties in treating dual diagnosis patients are exacerbated by the fact that most “psychiatric services have created a division between services for the management of these patients” (Buckley, 1998, p. 26). Specialized substance abuse programs are often distinct from services providing treatment for schizophrenia and other psychotic disorders (Buckley, 1998). Nevertheless, there is a broad consensus that dually diagnosed patients need programming that integrates both psychiatric and substance abuse treatment (Edwards & McGorry, 2002). The best results can be achieved when these two specialties are combined. These joint programs emphasize many of the 12-step approaches that are advocated in the treatment of primary alcoholism and substance abuse (Jerrell & Ridgely, 1995). In addition, they emphasize the development of social skills and behavioural management (Bennett, Bellack, & Gearon, 2001).

The Saskatoon Health Region has the organizational foundation to effectively link early psychosis treatment and addiction services. In December 2002, Saskatoon Health Region Mental Health Services and Addiction Services were joined in a partnership as one Care Group under one General Manager (Saskatoon Health Region, 2006). The challenge now is to operationalize this partnership. Formal assignment of an Addictions Worker to the EIP team would assist in creating more sustained treatment linkages between the two programs. This would also facilitate the development of expanded knowledge and expertise about the links between psychosis and substance use (Edwards & McGorry,

2002). Given the ambiguity that exists about the etiology of co-morbid substance use in psychosis, the EIP program may want to reassess its exclusion criteria for the admission of patients with a pre-existing substance use disorder.

7.4 Outcome

7.4.1 Reduced hospitalization and cost

From an administrative perspective, the primary outcome identified from the focus group discussions and cost analysis is that the EIP patients had a significantly lower cost of inpatient care with mean savings of $6950 per person. This result was supported by a consistent, but non-significant, reduction in hospital admissions, emergency room visits, emergency room costs and total SHR cost (including EIP cost). This is consistent with the overall savings found by Mihalopoulos et al of $6818 CAD per patient (in 1999 dollars) in the EPPIC program in Melbourne, Australia. Based on 29 EIP clients, this provides annual acute care savings of over $100,000. This is nearly double the cost of operating the EIP program for one year (about $50,000). Nevertheless, the Health Region has been reluctant to invest new resources in this program. The program was founded and continues to be operated with resources seconded from other Mental Health Programs. No doubt, a larger sample size and inclusion of additional in-patient costs such as overhead, inpatient medication costs, and other support services costs would substantiate even greater reductions in hospitalization costs.

8.0 CONCLUSIONS

8.1 Summary

Individuals with first-break psychosis face a shroud of fear, stigma and superstition that contributes to the profound impact of this disorder. Studies show that people with schizophrenia and other psychotic disorders are at a higher risk for a multitude of problems: suicide, substance abuse, homelessness, incarceration, employment difficulties and problems with interpersonal relationships. With an average age of onset in adolescence or early adulthood, the illness can delay personality maturation, strain social and family relationships, and place study/career plans on hold (Moller, 2005).

This client group, representing a mental illness with low incidence yet devastating consequences, has confounded traditional treatment methods. As a result, a pioneering approach known as *Early Intervention in Psychosis* gained recognition throughout the 1990s. While studied extensively from the clinical perspective, less is known about the managerial aspects of early psychosis services. This study examined, from an interdisciplinary administrative perspective, the structures and processes that support positive outcomes in early psychosis. This examination was undertaken by means of a case study across two eras of care (1990-1998 and 1999-2006) in the Saskatoon Health Region, a Canadian health region with a catchment population of about 300,000.

To lay the foundation for this study, an evaluability assessment was completed. This resulted in the development of an evaluable program model and a program logic model. This case study described the traditional model of care (1990 – 1998) and the early intervention model of care (1999- 2006). The study included 29 early intervention clients and 14 historical clients. The study was undertaken by means of a mixed methods approach consisting of assessments of early intervention clients, chart reviews of hospital in-patient admissions and emergency room visits, a cost analysis, a psychiatrist satisfaction survey, and two focus groups with EIP program stakeholders.

In response to the first study question, the study identified two elements of structure that contribute to the effective provision of early intervention services. First, it was concluded that a sustained and diverse interprofessional team is a prime contributor. Second, it was found that the “nested” program model contributes to effective provision of early intervention services by offering increased opportunities for coordination, integration and cost-effective service delivery. Next, the study identified one element of structure that detracts from the effective provision of early intervention services. It was concluded that staff stress and burn-out may impact the sustainability of the Early Intervention Program. New resources were not allocated for the creation of the EIP program and this had an effect on staff stress and burn-out.

In response to the second study question, the study identified one element of process that contributes to the effective provision of early intervention services. It was recognized that a strong school outreach and programming component will support effective early detection and appropriate early referral to

the program. The study also identified one element of process that detracts from the effective provision of early intervention services. It was recognized that issues associated with co-morbid substance abuse severely inhibit clients' progress toward recovery and remission. It was recommended that a closer working relationship between the EIP program and SHR addictions services would help ameliorate this situation.

In response to the third study question, one key administrative outcome was identified. Study results indicated a reduced cost of in-patient hospital care. Despite evidence of acute care savings, it appears to be administratively difficult to re-allocate these funding into out-patient programming such as early intervention due to organizational priorities, budget accountabilities and reporting relationships.

This study has a number of limitations that warrant discussion. For the most part the EIP client assessments were invalid or statistically inconclusive. This was due to the small sample size and was compounded by missing values. The pattern for missing values did not represent "loss to follow-up" but was random and sporadic. As stated by Bea Van Beveren and Hetherington (1997), community-based programs that are struggling for financial resources to maintain operations may not have the budget or technical resources to produce a scientifically sound evaluation design. As noted by Crossley et al (1997), it is important to make realistic estimates of time requirements for evaluation. In this regard, the data collection for the EIP would have benefited from the ongoing support of a research assistant to alleviate the data collection burden from the program psychiatric nurses. This aspect of the study had many weaknesses

that limit its usefulness. Nevertheless, the other aspects of the overall study offer valuable information about the structure, process and outcome of an Early Intervention in Psychosis program under “real-world” conditions.

8.2 Directions for future research

According to Donabedian's model, processes are constrained by the structures in which they operate (Donabedian, 1988). A useful avenue of future research could involve further exploration of the administrative aspects of early psychosis intervention, and the linkages between structure, process and outcome in early psychosis care. Specifically, the concept of the “nested” program could be further delineated with respect to other “contributors” or “detrators” to early psychosis care identified here, namely staff burn-out, funding and sustainability, and the role of the inter-professional team. How are these elements affected by the “nested” model and, conversely, how does the “nested” model impact these elements? Are the “nested” program and staff stress/burn out linked and, if so, how? As well, the relevance and application of the “nested” program model to other health sectors (e.g. general medicine, chronic disease management, etc.) would be an interesting line of research. This future work would lead to a stronger conceptual framework of organizational design and quality to assist mid-sized health regions in meeting the needs of low incidence and complex client groups including early psychosis.

8.3 Knowledge transfer

The Canadian Institutes of Health Research (2004) defined knowledge translation as “the exchange, synthesis and ethically-sound application of

knowledge - within a complex system of interactions among researchers and users - to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system." This research study fostered a number of opportunities for knowledge transfer including the following:

- the evaluable program model was presented to the Early Intervention in Psychosis team in June 2000;
- the preliminary study findings were presented at Psychiatry Grand Rounds, Royal University Hospital and College of Medicine in Fall 2001;
- interactive focus groups were held with Early Intervention in Psychosis stakeholders in June and September 2006 (a summary of the focus groups themes was provided to focus group participants);
- a summary of study results was provided to Saskatoon Health Region management in August 2007.

8.4 Closing remarks

Early intervention in psychosis is a difficult and important challenge for mental health services. Delayed detection and treatment of psychosis have serious consequences for public health. The "collateral damage" can be extensive and, as Lieberman and Fenton (2000, p. 1727) described, can impose "a significant burden of terror, suffering, and bewilderment on patients and their families." Over the past fifteen years, early intervention in psychosis has become a global movement. While some antagonists exist, a body of evidence

is growing in support of this approach. As clinical practices shift, administrative support structures need to respond accordingly. This means being attentive to the structures, process and outcomes of care from an administrative perspective. While clinicians will remain the “gatekeepers” of advancements in providing efficacious treatments, responsibility rests with health service administrators to provide a supportive environment. This includes providing services that are flexible and appropriate to the client population. Attention to human resource issues, funding challenges and organizational design elements will bolster program effectiveness. Early intervention programs will only be successfully implemented and sustained when they are adapted to the system’s special needs and opportunities.

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List of Appendices

Appendix A: Program Documents Reviewed

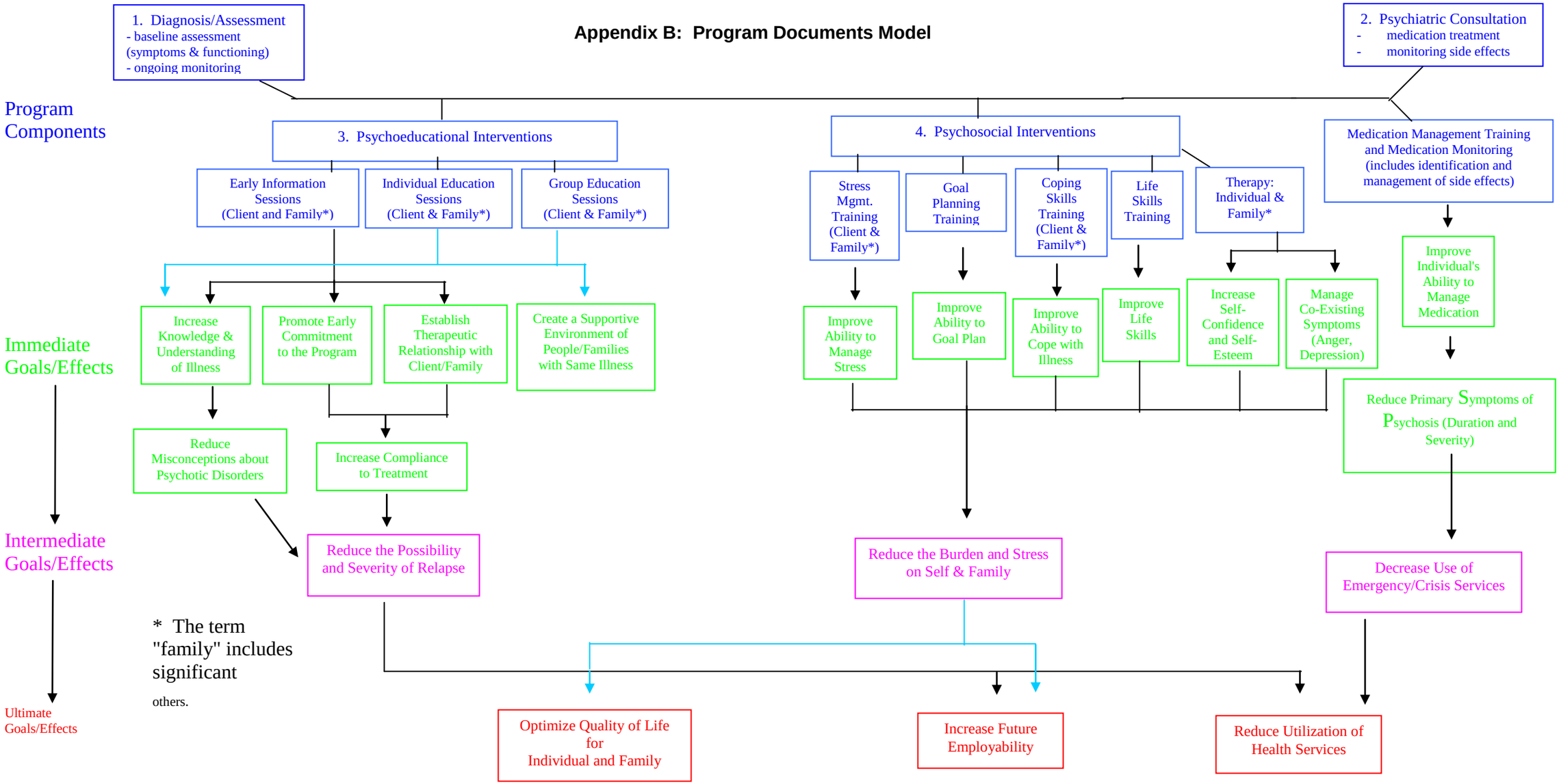
1. Program Brochure: *Early Intervention Program in Psychosis and Schizophrenia* (Spring 1999)

2. Early Intervention Program Manual (January 2000)

3. Discussion Paper: *Early Intervention Program in Psychosis and Schizophrenia* (1998)

4. Bonli, R., Owen, W.J., Phillips, D.F. *An Applied and Empirical Examination of Neuropsychological Measures Used in the Assessment of Individuals with Schizophrenia.* University of Saskatchewan. Unpublished Paper (Spring 1999).

Appendix B: Program Documents Model



Appendix C: Interview Schedule – Evaluability Assessment

Interviewer:
As you know, the purpose of this interview is to assist in preparing an Evaluability Assessment of the Early Intervention Program (EIP). The interview will take about an hour and fifteen minutes. Thank you for agreeing/consenting to be part of this process.

[To begin, the interviewer provides the respondent with a list of Definitions of the main terms used throughout the interview (i.e. program, component, activity, immediate goal, intermediate goal, ultimate goal, and effect). The list of Definitions is attached as Appendix D.]

Here is a list of the terms and definitions that will be used throughout this interview. Please feel free to refer to this sheet at any time during the interview. As you will see, these terms and definitions are laid out in a similar manner to the program model for easy reference.

Do you have any questions before we begin?

[Now the interviewer shows the respondent the Program Documents Model of the Early Intervention Program.]

The model before you includes all the components and related goals of the Early Intervention Program as described in the various program documents that I have analyzed.

First, I would like to discuss with you the components of the Early Intervention Program as depicted by the program documents.

*[The interviewer reads the following while reviewing **only** the program components with the respondent.]*

The Early Intervention Program is comprised of four main components, which are Diagnosis and Assessment, Psychiatric Consultation, Psychoeducational Interventions and Psychosocial Interventions. The program components of Psychoeducational Interventions are Early Information Sessions, Individual Information Sessions and Group Education Sessions. The program components of Psychosocial Interventions are, Stress Management Training, Goal Planning Training, Coping Skills Training, and Therapy. Medication Management Training is a program component related to Psychiatric Consultation. Assessment and Diagnosis and Psychiatric Consultation are over-arching program components which impact the other program components.

Please take about five minutes to examine the components of the program before we begin to discuss whether you feel that these descriptions are accurate.

[The interviewer points out the components of the model that are to be examined.]

Do you have any questions or comments before we continue?

[For questions 1 to 73, the interviewer points out each component that will be discussed.]

The following questions will focus on the Early Intervention Program's components and corresponding activities as you understand them. That is, in this section of the interview, I want to know how each component operates.

1. Is the first component, *Assessment and Diagnosis*, part of the EIP?

A. Yes
B. No

IF NO 2. Please explain why not?

IF YES 3. a) What activities are involved in the component *Assessment and Diagnosis* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

4. Is the second component, *Psychiatric Consultation*, part of the EIP?

A. Yes
B. No

IF NO 5. Please explain why not?

IF YES 6. a) What activities are involved in the component *Psychiatric Consultation* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

7. Is the third component, *Early Information Sessions*, part of the EIP?

A. Yes
B. No

IF NO 8. Please explain why not?

IF YES 9. What is meant by the term *Early Information*?

10. a) What activities are involved in the component *Early Information Sessions* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

11. Is the fourth component, *Individual Education Sessions*, part of the EIP?

A. Yes
B. No

IF NO 12. Please explain why not?

IF YES 13. What is meant by the term *Education Sessions*?

14. a) What activities are involved in the component *Individual Education Sessions* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

15. Is the fifth component, *Group Education Sessions*, part of the EIP?

A. Yes
B. No

IF NO 16. Please explain why not?

IF YES 17. What is meant by the term *Group Education*?

18. a) What activities are involved in the component *Group Education Sessions* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

19. Is the seventh component, *Stress Management Training*, part of the EIP?

A. Yes
B. No

IF NO 20. Please explain why not?

IF YES 21. What is meant by the term *Stress Management*?

22. a) What activities are involved in the component *Stress Management Training* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

23. Is the eighth component, *Goal Planning Training*, part of the EIP?

A. Yes
B. No

IF NO 24. Please explain why not?

IF YES 25. What is meant by the term *Goal Planning*?

26. a) What activities are involved in the component *Goal Planning Training* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

27. Is the ninth component, *Coping Skills Training*, part of the EIP?

A. Yes
B. No

IF NO 28. Please explain why not?

IF YES 29. What is meant by the term *Coping Skills*?

30. a) What activities are involved in the component *Coping Skills Training* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

31. Is the tenth component, *Life Skills Training*, part of the EIP?

A. Yes
B. No

IF NO 32. Please explain why not?

IF YES 33. What is meant by the term *Life Skills Training*?

34. a) What activities are involved in the component *Life Skills Training* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

35. Is the eleventh component, *Individual and Family Therapy*, Part of the EIP?

A. Yes
B. No

IF NO 36. Please explain why not?

IF YES 37. What is meant by the term *Therapy*?

38. a) What activities are involved in the component *Individual and Family Therapy* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

39. Is the twelfth component, *Medication Management Training and Medication Monitoring*, part of the EIP?

A. Yes
B. No

IF NO 40. Please explain why not?

IF YES 41. What is meant by the terms *Medication Management and Medication Monitoring*?

42. a) What activities are involved in the component *Medication Management Training and Medication Monitoring* (i.e. how does this component of the program operate)?

b) Is this component labeled appropriately?

43. Are there any other program components that have not been mentioned in the model but that you feel are important to the structure and function of the program?

A. Yes
B. No

IF NO, GO TO PART II

IF YES 44. Please describe these components for me.

II. Now I would like to discuss the expected goals and effects that these components are designed to achieve as depicted by the program model.

[The interviewer reads the following while going through the program goals/effects of the program model with the respondent. ***Remind*** *the respondent about the definitions for immediate, intermediate, and ultimate goals and effects.]*

A. The program components and activities lead to fourteen immediate goals (identified in green). The first goal is to increase the individual and family's knowledge and understanding of their illness, which fosters the second goal of reducing misconceptions about psychotic disorders. The second and third goals are to promote early commitment to the program and to establish a therapeutic relationship with the client, which promote the fifth goal of increasing compliance to treatment. The sixth goal is to create a supportive environment of people and families with the

same illness. The seventh goal is to improve the ability of clients and families to manage stress. The eighth goal is to increase the individual's ability to goal plan. The ninth goal is to improve the client and family's ability to cope with the illness. The tenth goal is improve the client's life skills. The eleventh goal is to increase the client's self-confidence and self-esteem. The twelfth goal is to manage co-existing symptoms such as anger and depression. The thirteenth goal is to improve the individual's ability to manage medications, which promotes the fourteenth goal of reducing the primary symptoms of psychosis.

[The interviewer goes through each of the goals in the model and asks the respondent the following specific questions for each goal.]

A 45. First, I would like you to consider the first goal, *increase knowledge and understanding of illness*.

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the Choice Sheet (Appendix E), explaining that the respondent is asked to fill in the blanks.]

45-a Do you feel that *increase knowledge and understanding of illness* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

45-b Please explain how *increase knowledge and understanding of illness* is _____.

IF ANSWERED A, B, or C ABOVE, GO TO 45-c and 45-d
IF ANSWERED D, E or F, THEN GO TO QUES. #A 46

45-c Can you give me an example of what it means when you say, "*increase knowledge and understanding of illness* as a goal of the EIP"?

45-d What kinds of evidence would convince you that the goal *increase knowledge and understanding of illness* has been achieved? (Probe: Is this information collected?)

A 46. I would now like you to consider the second goal *reduce misconceptions about psychotic disorders*.

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

46-a Do you feel that *reduce misconceptions about psychotic disorders* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

46-b Please explain how *reduce misconceptions about psychotic disorders* is _____.

IF ANSWERED A, B, or C ABOVE, GO TO 46-c and 46-d IF ANSWERED D, E or F, THEN GO TO QUES. #A 47

46-c. What does *reduce misconceptions about psychotic disorders* mean as a goal of the EIP? (Probe: Can you give me an example?)

46-d. What kinds of evidence would convince you that the goal *reduce misconceptions about psychotic disorders* has been achieved? (Probe: Is this information collected?)

A 47. I would like you to consider the third goal *promote early commitment to the program*.

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

47-a Do you feel that *promote early commitment to the program* is _____ of the EIP.

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

47-b Please explain how *promote early commitment to the program improve* is _____.

IF ANSWERED A, B, or C ABOVE, GO TO 47-c and 47-d
IF ANSWERED D, E or F, THEN GO TO QUES. #A 48

47-c What does *promote early commitment to the program* mean as a goal of the EIP? (Probe: Can you give me an example?)

47-d What kinds of evidence would convince you that the goal *promote early commitment to the program* has been achieved? (Probe: Is this information collected?)

A 48. I would like you to consider the fourth goal *establish therapeutic relationship with client and family*.

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

48-a Do you feel that *establish therapeutic relationship with client and family* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

48-b Please explain how *establish therapeutic relationship with client and family* is _____.

IF ANSWERED A, B, or C ABOVE, GO TO 48-c and 48-d
IF ANSWERED D, E or F, THEN GO TO QUES. #A 49

48-c What does *establish therapeutic relationship with client and family* mean as a goal of the EIP? (Probe: Can you give me an example?)

48-d What kinds of evidence would convince you that the goal *establish therapeutic relationship with client and family* has been achieved? (Probe: Is this information collected?)

A 49. I would like you to consider the fifth goal *increase adherence to treatment.*

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

49-a Do you feel that *increase adherence to treatment* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

49-b Please explain how *increase adherence to treatment* is _____.

IF ANSWERED A, B, or C ABOVE, GO TO 49-c and 49-d
IF ANSWERED D, E or F, THEN GO TO QUES. #A 50

49-c What does *increase adherence to treatment* mean as a goal of the EIP? (Probe: Can you give me an example?)

49-d What kinds of evidence would convince you that the goal *increase adherence to treatment* has been achieved? (Probe: Is this information collected?)

A 50. I would like you to consider the sixth goal *create a supportive environment of people and families with the same illness*.

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

50-a Do you feel that *create a supportive environment of people and families with the same illness* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

50-b Please explain how *create a supportive environment of people and families with the same illness* is _____.

IF ANSWERED A, B, or C ABOVE, GO TO 50-c and 50-d
IF ANSWERED D, E or F, THEN GO TO QUESTION #A 51.

50-c What does *create a supportive environment of people and families with the same illness* mean as a goal of the EIP? (Probe: Can you give me an example?)

50-d What kinds of evidence would convince you that the *create a supportive environment of people and families with the same illness* has been achieved? (Probe: Is this information collected?)

A 51. Now, I would like you to consider the seventh goal *improve ability to manage stress*.

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

51-a Do you feel that *improve ability to manage stress* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

51-b Please explain how *improve ability to manage stress* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 51-c and 51-d
IF ANSWERED D, E or F, THEN GO TO QUESTION #A 52

51-c What does *improve ability to manage stress* mean as a goal of the EIP? (Probe: Can you give me an example?)

51-d What kinds of evidence would convince you that the goal *improve ability to manage stress* has been achieved? (Probe: Is this information collected?)

A 52. Now, I would like you to consider the eighth goal *improve ability to goal plan*.
[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

52-a Do you feel that *improve ability to goal plan* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

52-b Please explain how is *improve ability to goal plan* an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 52-c and 52-d IF ANSWERED D, E or F, THEN GO TO QUESTION #A 53

52-c What does *improve ability to goal plan* mean as a goal of the EIP? (Probe: Can you give me an example?)

52-d What kinds of evidence would convince you that the goal *improve ability to goal plan* has been achieved? (Probe: Is this information collected?)

A 53. Now, I would like you to consider the ninth goal *improve ability to cope with illness*.

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

53-a Do you feel that *improve ability to cope with illness* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

53-b Please explain how *improve ability to cope with illness* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 53-c and 53-d IF ANSWERED D, E or F, THEN GO TO QUESTION #A 54

53-c What does *improve ability to cope with illness* mean as a goal of the EIP? (Probe: Can you give me an example?)

53-d What kinds of evidence would convince you that the goal *improve ability to cope with illness* has been achieved? (Probe: Is this information collected?)

A 54. Now, I would like you to consider the tenth goal *improve life skills*.

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

54-a Do you feel that *improve life skills* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

54-b Please explain how *improve life skills* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 54-c and 54-d IF ANSWERED D, E or F, THEN GO TO QUESTION #A 55

54-c What does *improve life skills* mean as a goal of the EIP? (Probe: Can you give me an example?)

54-d What kinds of evidence would convince you that the goal *improve life skills* has been achieved? (Probe: Is this information collected?)

A 55. Now, I would like you to consider the eleventh goal *increase self-confidence and self-esteem*.

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

55-a Do you feel that *increase self-confidence and self-esteem* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

55-b Please explain how *increase self-confidence and self-esteem* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 55-c and 55-d IF ANSWERED D, E or F, THEN GO TO QUESTION #A 56

55-c What does *increase self-confidence and self-esteem* mean as a goal of the EIP? (Probe: Can you give me an example?)

55-d What kinds of evidence would convince you that the goal *increase self-confidence and self-esteem* has been achieved? (Probe: Is this information collected?)

A 56. Now, I would like you to consider the twelfth goal *manage co-existing symptoms (such as anger and depression).*

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

56-a Do you feel that *manage co-existing symptoms (such as anger and depression*) is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

56-b Please explain how *manage co-existing symptoms (such as anger and depression*) is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 56-c and 56-d
IF ANSWERED D, E or F, THEN GO TO QUESTION #A 57

56-c What does *manage co-existing symptoms (such as anger and depression*)mean as a goal of the EIP? (Probe: Can you give me an example?)

56-d What kinds of evidence would convince you that the *manage co-existing symptoms (such as anger and depression*) has been achieved? (Probe: Is this information collected?)

A 57. Now, I would like you to consider the thirteenth goal *improve individual's ability to manage medication*.

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

57-a Do you feel that *improve individual's ability to manage medication* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal

C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

57-b Please explain *improve individual's ability to manage medication* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 57-c and 57-d
IF ANSWERED D, E or F, THEN GO TO QUESTION #A 58

57-c What does *improve individual's ability to manage medication* mean as a goal of the EIP? (Probe: Can you give me an example?)

57-d What kinds of evidence would convince you that *improve individual's ability to manage medication* has been achieved? (Probe: Is this information collected?)

A 58. Now, I would like you to consider the fourteenth goal *reduce primary symptoms of psychosis (duration and severity).*

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

58-a Do you feel that *reduce primary symptoms of psychosis (duration and severity)* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

58-b Please explain how *reduce primary symptoms of psychosis (duration and severity)* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 58-c and 58-d
IF ANSWERED D, E or F, THEN GO TO QUESTION #A 59

58-c What does *reduce primary symptoms of psychosis (duration and severity)* mean as a goal of the EIP? (Probe: Can you give me an example?)

58-d What kinds of evidence would convince you that the *reduce primary symptoms of psychosis (duration and severity)* has been achieved? (Probe: Is this information collected?)

There are three intermediate goals (identified in pink). The first intermediate goal is to reduce the possibility and severity of relapse. The second intermediate goal is to reduce the burden and stress on self and family. The third intermediate goal is to decrease the use of emergency and crisis services.

A 59. Now, I would like you to consider the first intermediate goal *reduce the possibility and severity of relapse.*

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

59-a Do you feel that *reduce the possibility and severity of relapse* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

59-b Please explain how *reduce the possibility and severity of relapse* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 59-c and 59-d
IF ANSWERED D, E or F, THEN GO TO QUESTION #A 60

59-c What does *reduce the possibility and severity of relapse* mean as a goal of the EIP? (Probe: Can you give me an example?)

59-d What kinds of evidence would convince you that the *reduce the possibility and severity of relapse* has been achieved? (Probe: Is this information collected?)

A 60. Now, I would like you to consider the second intermediate goal *reduce the burden and stress on self and family.*

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

60-a Do you feel that *reduce the burden and stress on self and family* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

60-b Please explain how *reduce the burden and stress on self and family* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 60-c and 60-d IF ANSWERED D, E or F, THEN GO TO QUESTION #A 61

60-c What does *reduce the burden and stress on self and family* mean as a goal of the EIP? (Probe: Can you give me an example?)

60-d What kinds of evidence would convince you that the *reduce the burden and stress on self and family* has been achieved? (Probe: Is this information collected?)

A 61. Now, I would like you to consider the third intermediate goal *decrease use of emergency/crisis services.*

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

61-a Do you feel that *decrease use of emergency/crisis services* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

61-b Please explain how *decrease use of emergency/crisis services* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 61-c and 61-d IF ANSWERED D, E or F, THEN GO TO QUESTION #A 62

61-c What does *decrease use of emergency/crisis services* mean as a goal of the EIP? (Probe: Can you give me an example?)

61-d What kinds of evidence would convince you that the goal *decrease use of emergency/crisis services* has been achieved? (Probe: Is this information collected?)

Now we will consider the three ultimate goals of the program (identified in red): 1) to optimize quality of life (of the individual and their family, 2) to increase future employability, and 3) to reduce utilization of health services.

A 62. I would like you to consider the eighteenth goal *optimize quality of life for individual and family.*

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

62-a Do you feel that *optimize quality of life for individual and family* is_____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

62-b Please explain how *optimize quality of life for individual and family* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 62-c and 62-d
IF ANSWERED D, E or F, THEN GO TO QUESTION #A 63

62-c What does *optimize quality of life for individual and family* mean as a goal of the EIP? (Probe: Can you give me an example?)

62-d What kinds of evidence would convince you that the goal *optimize quality of life for individual and family* has been achieved? (Probe: Is this information collected?)

A 63. Now, I would like you to consider the nineteenth goal *increase future employability.*

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

63-a Do you feel that *increase future employability* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other: _____
F. I do not know

63-b Please explain how *increase future employability* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 63-c and 63-d
IF ANSWERED D, E or F, THEN GO TO QUESTION #A 64

63-c What does *increase future employability* mean as a goal of the EIP? (Probe: Can you give me an example?)

63-d What kinds of evidence would convince you that the goal *increase future employability* has been achieved? (Probe: Is this information collected?)

A 64. Now, I would like you to consider the twentieth goal *reduce utilization of health services.*

[The interviewer points to this goal on the model when making this statement, and then refers the respondent to the choice sheet.]

64-a Do you feel that *reduce utilization of health services* is _____ of the EIP?

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the EIP
E. other:_____
F. I do not know

64-b Please explain how *reduce utilization of health services* is an _____.

IF ANSWERED A, B, or C ABOVE, GO TO 64-c and 64-d
IF ANSWERED D, E or F, THEN GO TO <u>SECTION B</u>.

64-c What does *reduce utilization of health services* mean as a goal of the EIP? (Probe: Can you give me an example?)

64-d What kinds of evidence would convince you that the goal *reduce utilization of health services* has been achieved? (Probe: Is this information collected?)

B. Now I would like to ask you some general questions about the program goals.

B. 65. Are there any other goals or effects that have not been mentioned in the model that you feel are important to the structure and functioning of the program?

A. Yes
B. No

IF NO, GO TO QUESTION 67

IF YES: 66. Please describe these goals or effects to me.

B. 67. Are there any unintentional effects of the program you feel are important to mention? (Probe: Clarify whether positive or negative effects.)

A. Yes
B. No

IF NO, GO TO QUESTION 69

IF YES: 68. Please describe these unintentional effects to me.

B. 69. Are there any conflicting goals in this model?

[The interviewer defines "conflicting goals" for the respondent as follows: "a situation in which the accomplishment of one goal is at the expense of another."]

A. Yes
B. No

If NO, GO TO QUESTION 71

IF YES: 70. Please explain which goals are in conflict and the nature of the conflict.

B. 71. Are there any goals that much be de-emphasized to reach another goal (or goals)?

A. Yes
B. No

IF NO, GO TO Section III

IF YES: 72. Please elaborate on why these goals need to be de-emphasized.

III. I would now like to discuss the links between the program components and the goals; that is, the way the components are expected to produce goals or effects.

[The interviewer now presents to the respondent the model that shows the program components, but that does not show the links between them.]

73. Using this model, please show me how you see the program components and their goals and effects to be linked by drawing in the links yourself.

This concludes the interview. Do you have any comments that you would like to make before I leave?

Do you have any questions?

Concluding remarks:

Thank you for your time. Here is a copy of the definitions for your files/reference. I will be drawing a model of the program from the information you have just given me. Then I will be contacting you again to make sure this model accurately reflects your views. Later, the findings from all of the interviews will be amalgamated into a single model which will be presented in a confidential report that will be given to my agency supervisor, Dr. David Keegan. Please feel free to contact me or Dr. Keegan if you have any questions or comments.

Record for each interview:

Name of Interviewee: _____
Position/Role: _____
Phone Number: _____
Date of Interview: _____
Time interview started: _____
Time interview ended: _____
Total time: _____
Draft model provided: _____
Modifications required? Yes____ No____

Appendix D: Definitions

Program: An organized effort devoted to a particular service, i.e. the Early Intervention Program.

Program Components: Those activities or sets of activities that directly impact on the clients or their social problems; they produce the stated goals/effects.

Activity: Any effort aimed at achieving a goal or goals of the program.

Immediate Goal: A goal of the program that must be achieved before any further outcomes can be achieved.

Intermediate Goal: An outcome of the program that is expected to occur as a result of proper implementation of the program.

Ultimate Goal: A goal that reflects the purpose of the program; the desired outcome of the program.

Effect: The results/consequences of participating in the program.

Adapted from: Clark and Grant (1998)

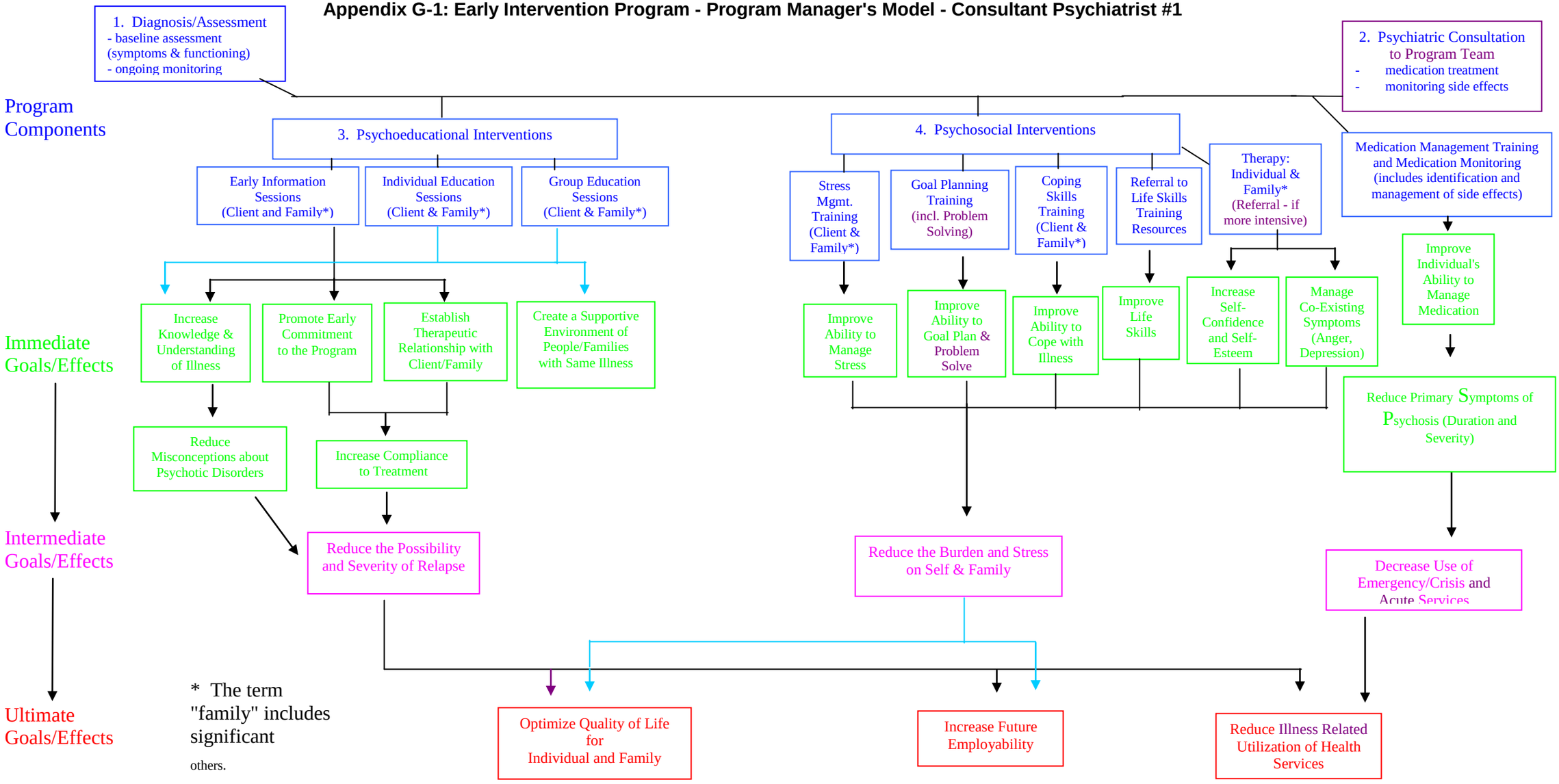
Appendix E: Choice Sheet

A. an immediate goal
B. an intermediate goal
C. an ultimate goal
D. not a goal of the Early Intervention Program
E. other: _____
F. I do not know

Appendix F: Interview Time Table

Individual/Group	Rationale	Interview Date
Consultant Psychiatrist and Professor, College of Medicine #1	One of two consultant psychiatrists to the program. He was instrumental to its development and ongoing operation. He was the former Head of Psychiatry for Saskatoon District Health (1993-98) and Royal University Hospital (1989-98), so brings considerable administrative as well as clinical expertise to the Program.	February 21 & 28, 2000
Consultant Psychiatrist and Professor, College of Medicine #2	One of two Consultant Psychiatrists to the Program. He is instrumental to its development and ongoing evaluation. A professor in the College of Medicine, he brings significant expertise in clinical practice and research.	May 10, 2000
Program Psychiatric Nurse #1	A registered psychiatric nurse, brings 20 years experience in acute and community-based mental health services. She was instrumental to the development and ongoing operation of the program.	March 3, 2000
Program Psychiatric Nurse #2	A registered psychiatric nurse, brings 20 years experience in acute and community-based mental health services. He was instrumental to the program's development and ongoing operation.	March 3, 2000
Manager, Adult Mental Health Services	The administrative head of the program, with line management responsibility and budget accountability. An occupational therapist by training, he also holds a Master's degree in health services administration. *Note: This manage resigned from his position effective May 2000.*	April 5, 2000
Clients (and their family members) admitted to the Program from May 15 - Nov. 15, 1999 (2 clients/ 2 family members)	It is important to obtain the consumer's perspective of the Program's components, objectives, goals and effects. Client confidentiality will be maintained when reporting interview results.	April 20 & 28, 2000

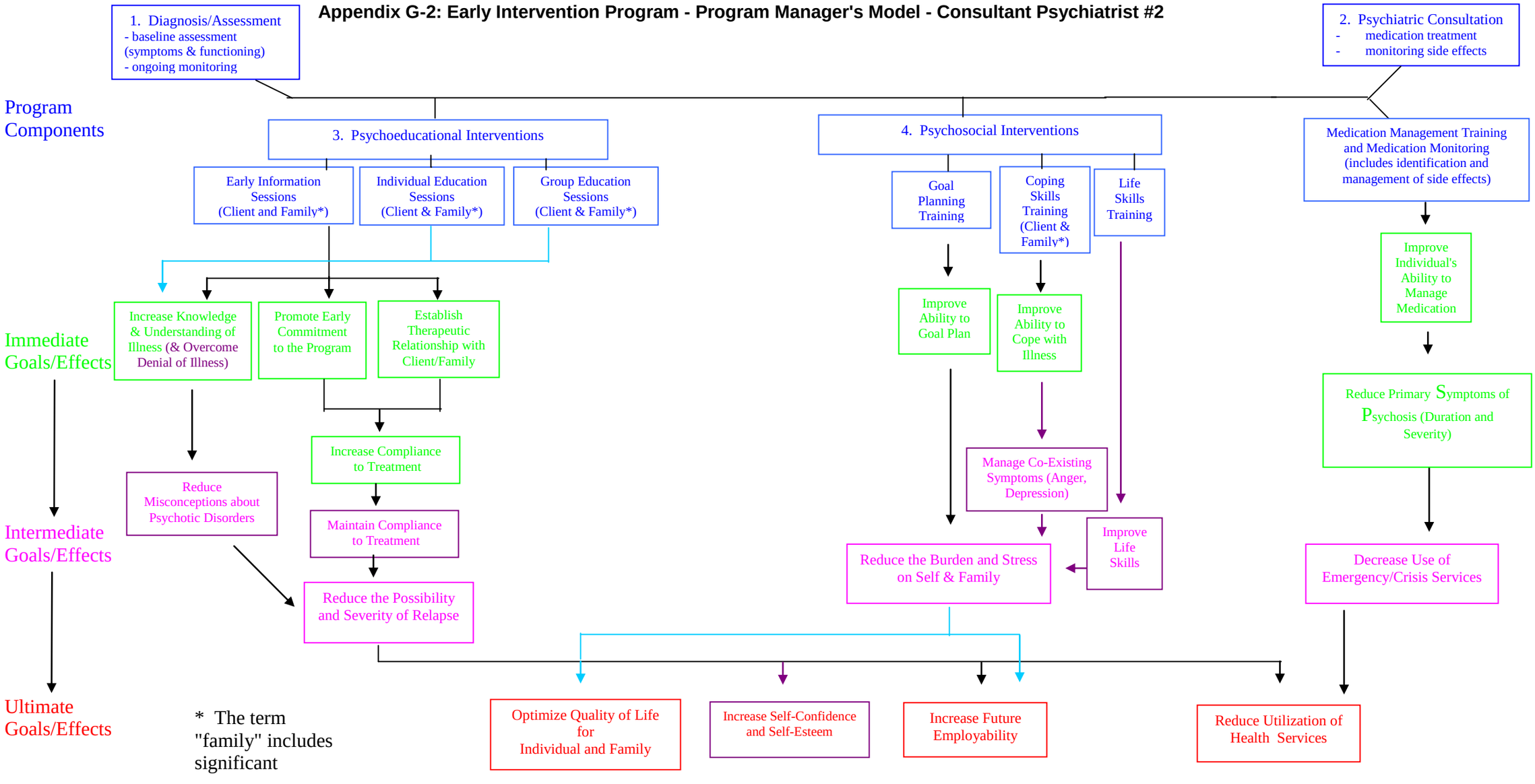
Appendix G-1: Early Intervention Program - Program Manager's Model - Consultant Psychiatrist #1



* The term "family" includes significant others.

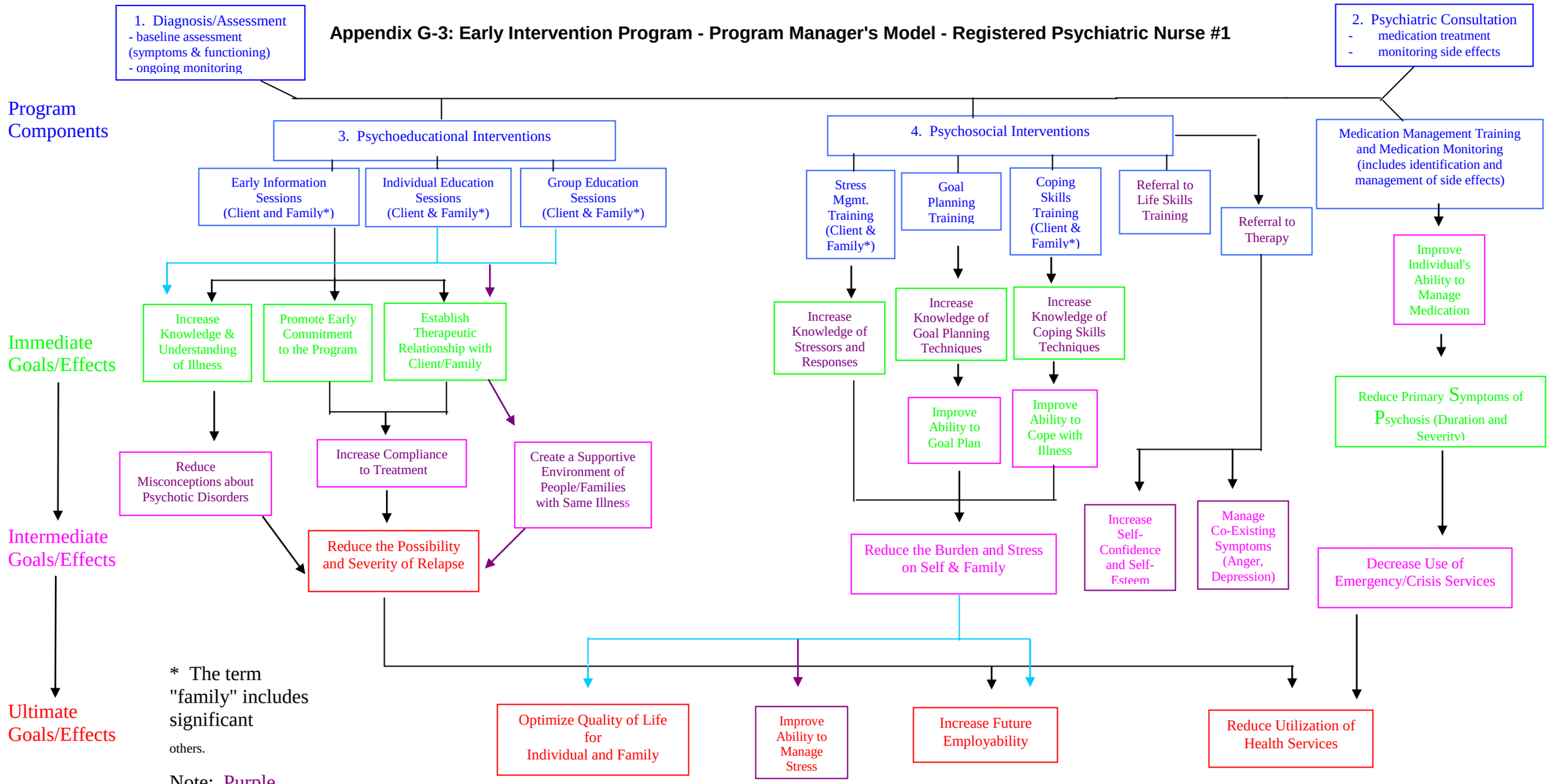
Note:

Appendix G-2: Early Intervention Program - Program Manager's Model - Consultant Psychiatrist #2



* The term "family" includes significant others.

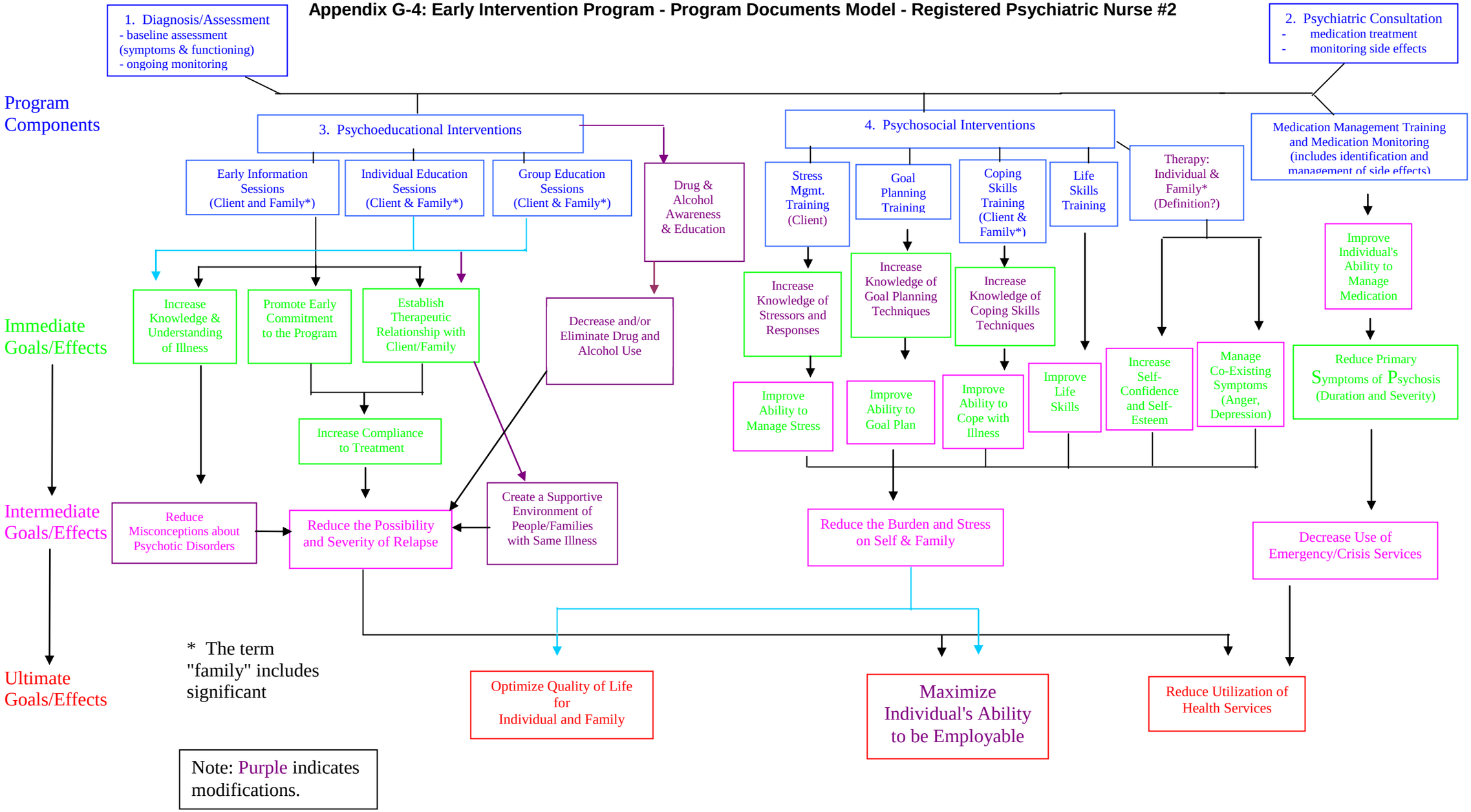
Appendix G-3: Early Intervention Program - Program Manager's Model - Registered Psychiatric Nurse #1



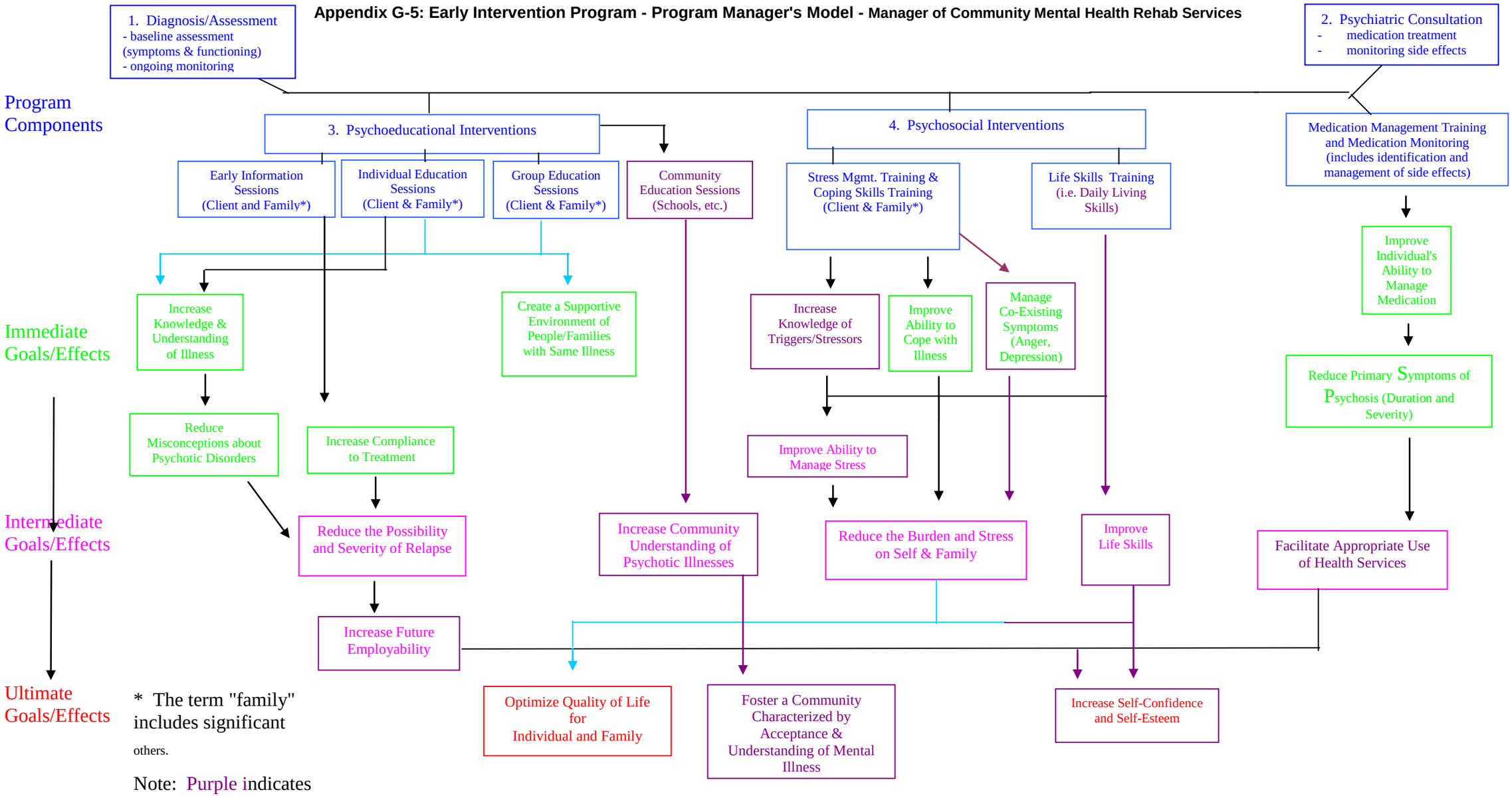
* The term "family" includes significant others.

Note: Purple indicates

Appendix G-4: Early Intervention Program - Program Documents Model - Registered Psychiatric Nurse #2



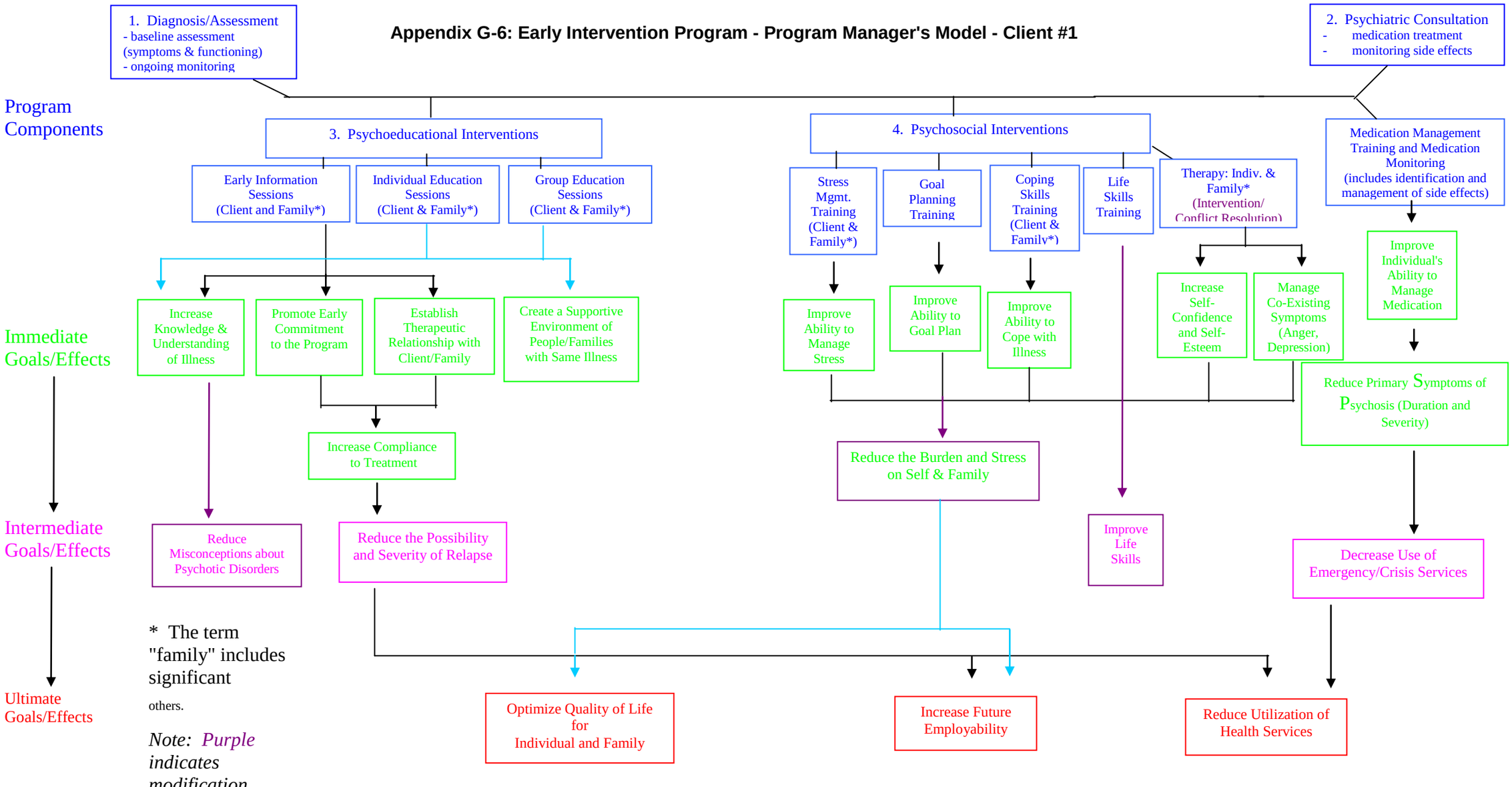
Appendix G-5: Early Intervention Program - Program Manager's Model - Manager of Community Mental Health Rehab Services



* The term "family" includes significant others.

Note: Purple indicates modification.

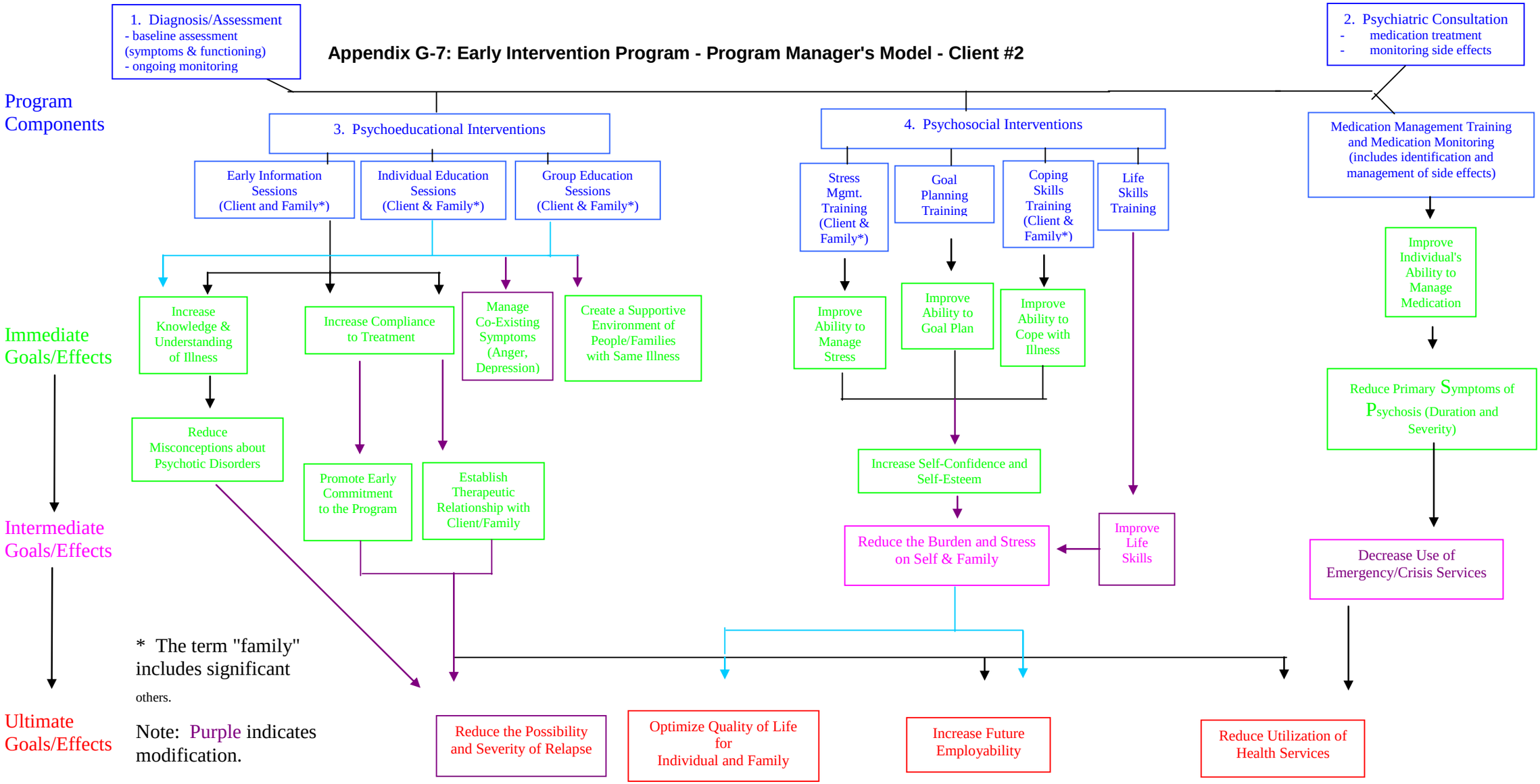
Appendix G-6: Early Intervention Program - Program Manager's Model - Client #1



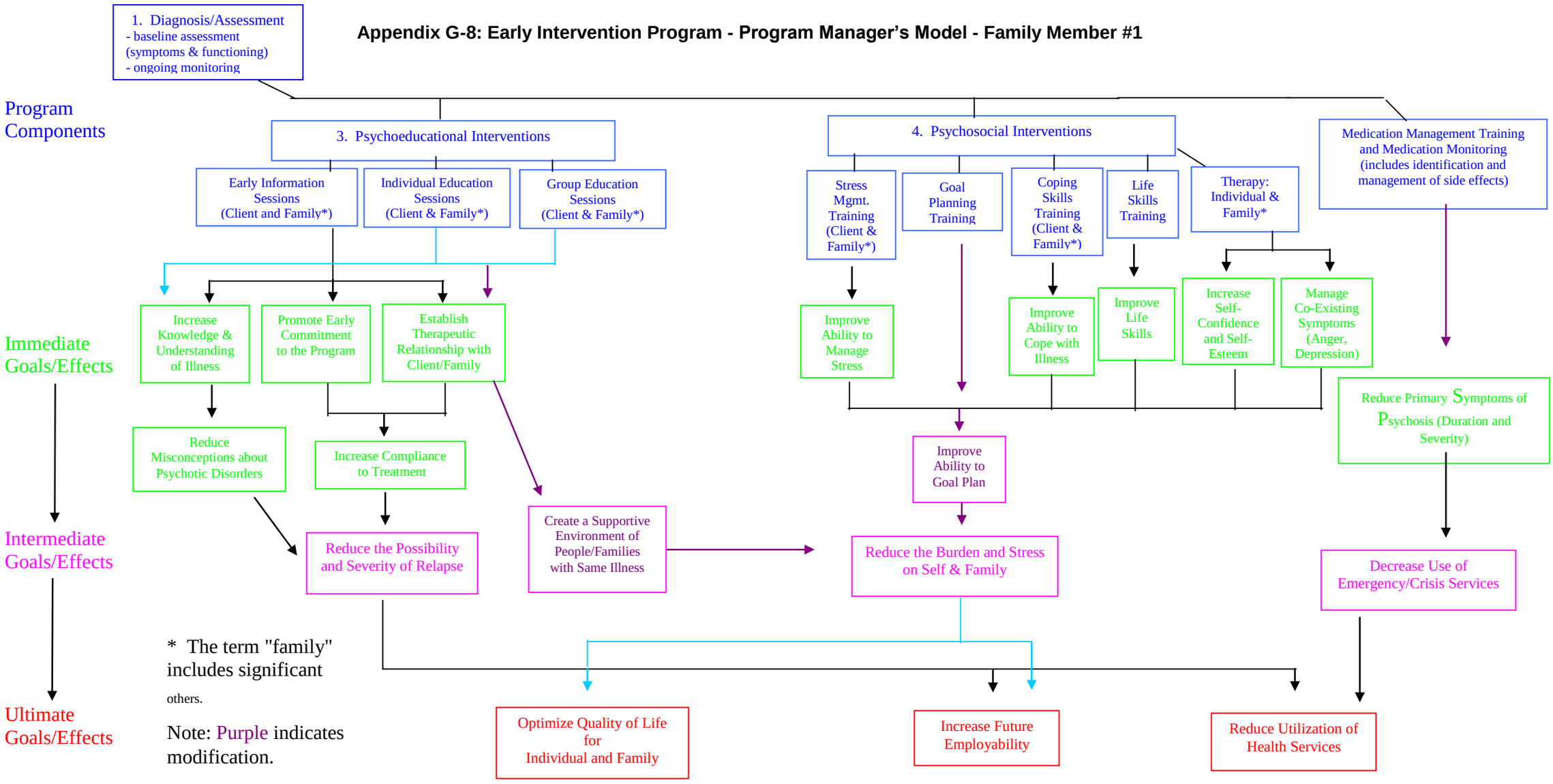
* The term "family" includes significant others.

Note: Purple indicates modification.

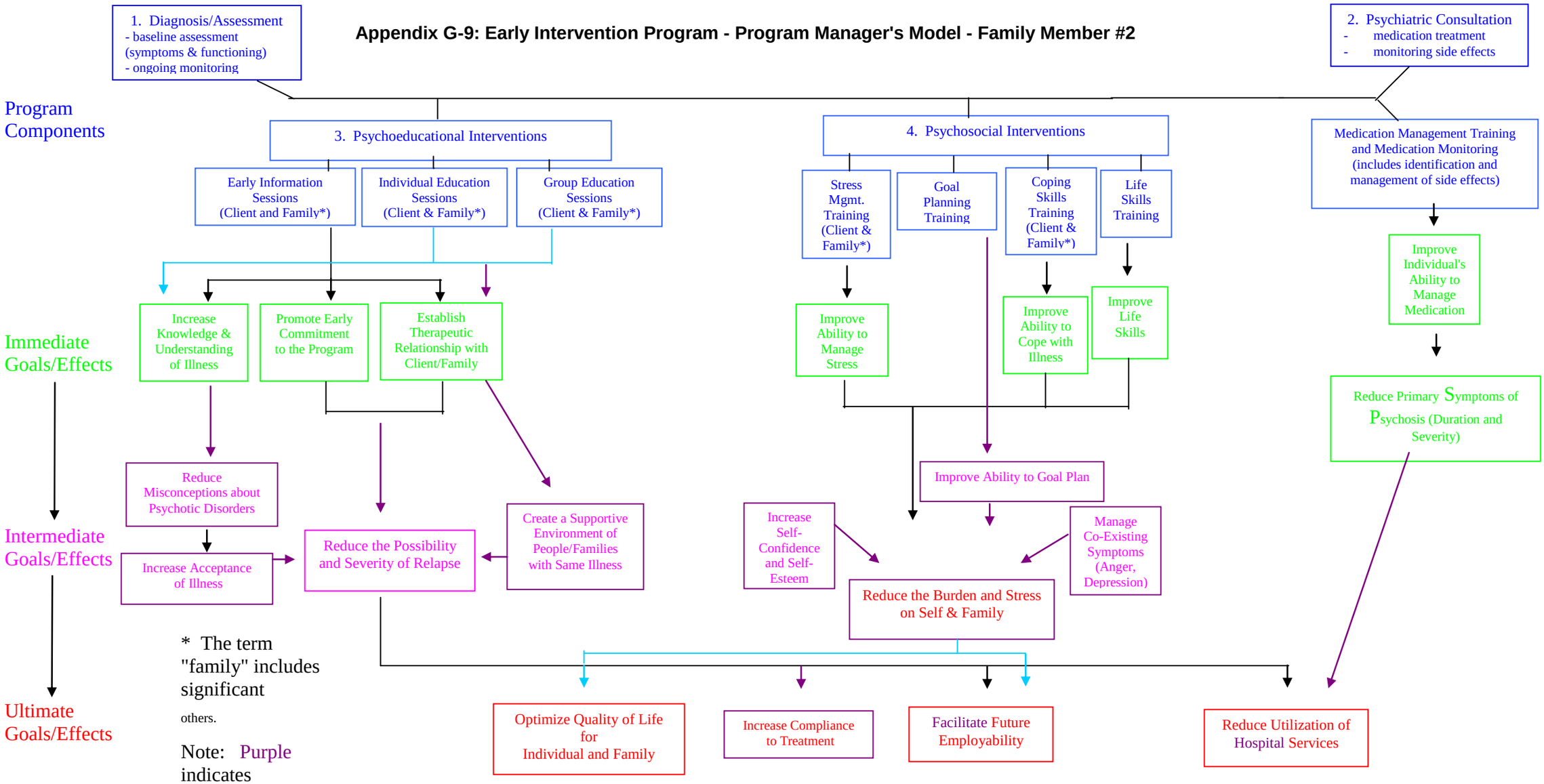
Appendix G-7: Early Intervention Program - Program Manager's Model - Client #2



Appendix G-8: Early Intervention Program - Program Manager's Model - Family Member #1



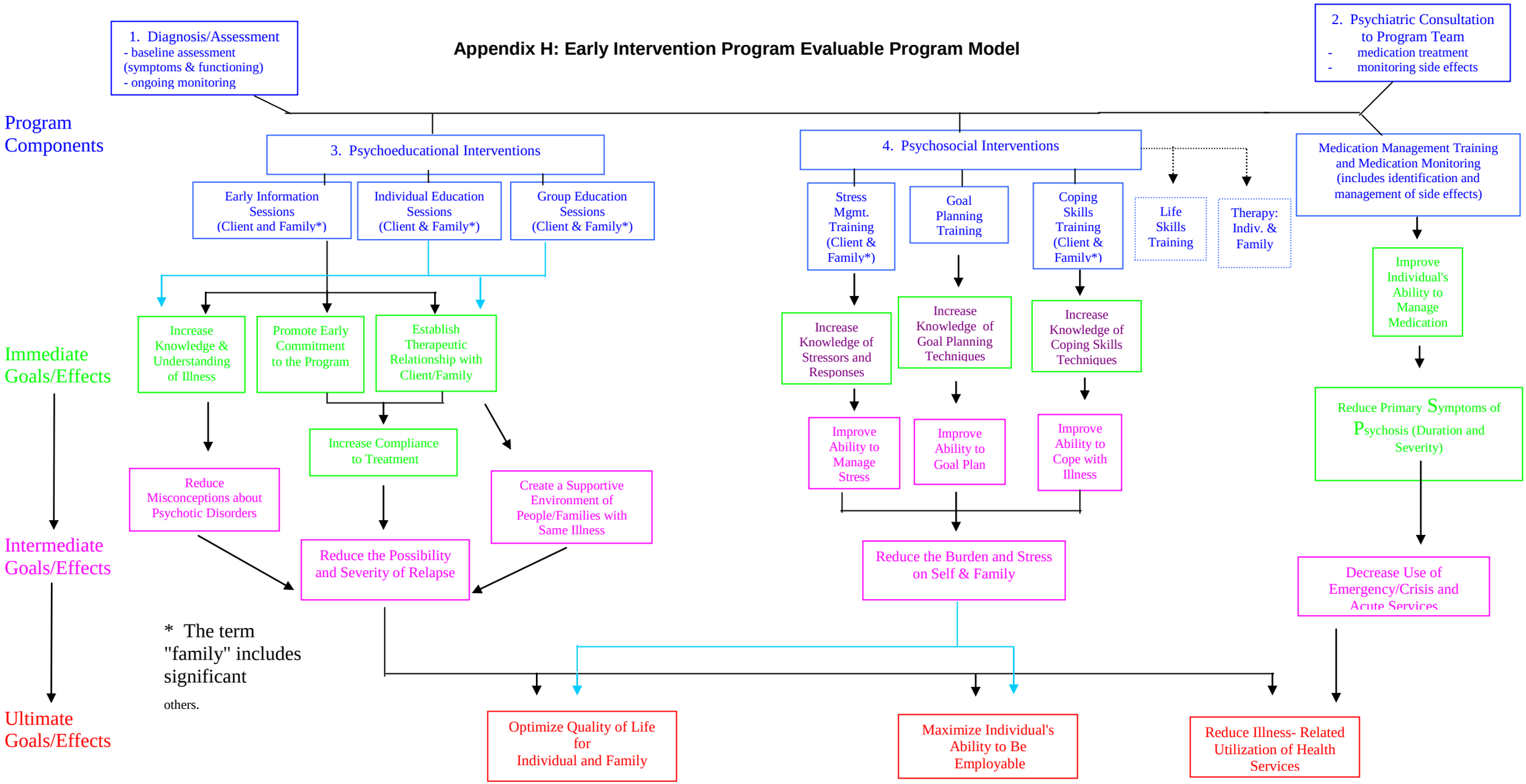
Appendix G-9: Early Intervention Program - Program Manager's Model - Family Member #2



* The term "family" includes significant others.

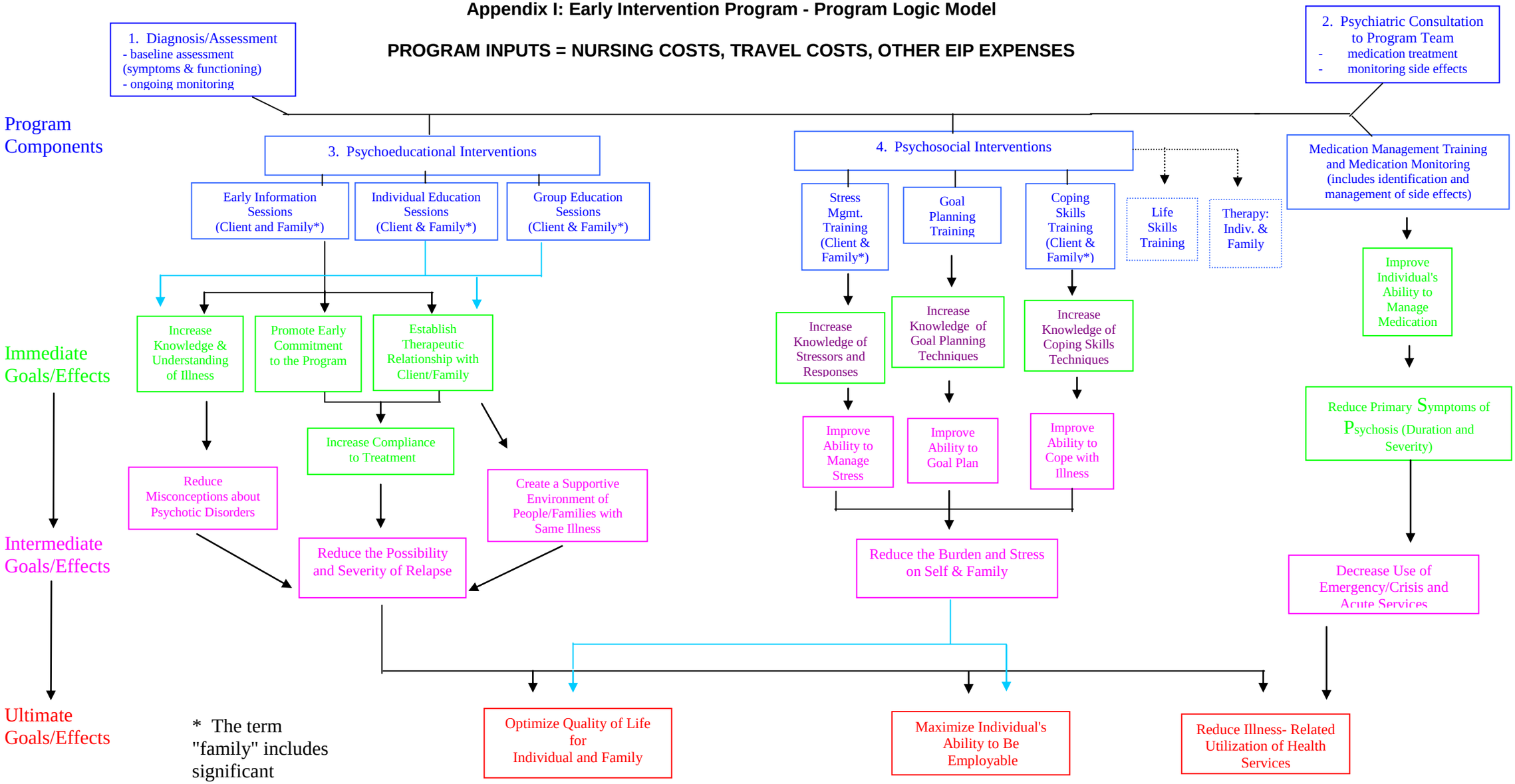
Note: Purple indicates modifications.

Appendix H: Early Intervention Program Evaluable Program Model



Appendix I: Early Intervention Program - Program Logic Model

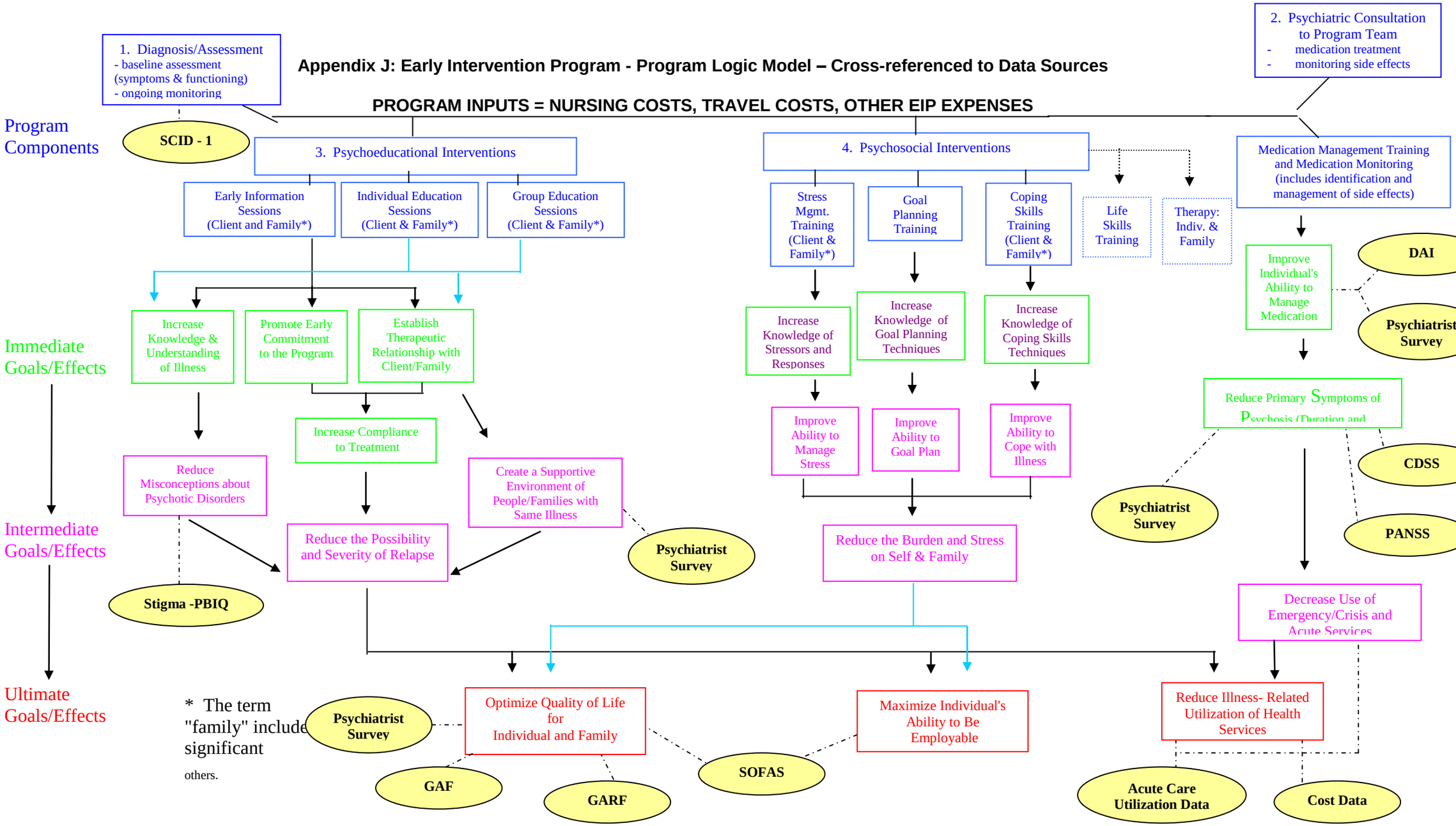
PROGRAM INPUTS = NURSING COSTS, TRAVEL COSTS, OTHER EIP EXPENSES



* The term "family" includes significant others.

Appendix J: Early Intervention Program - Program Logic Model – Cross-referenced to Data Sources

PROGRAM INPUTS = NURSING COSTS, TRAVEL COSTS, OTHER EIP EXPENSES



Focus Group Themes – potentially assess all immediate, intermediate and/or ultimate goals/effects.

Appendix K: Psychiatrist Survey

Early Intervention Program (EIP) – Evaluation of Services

1. What were the primary and secondary diagnoses that you made for the patient in question? Primary:_____
   Secondary:_____
   Were you able to formulate a prognosis?
   ☐ Yes ☐ No ☐ Special Issues, please specify:_____

2. What was your patient's insight or their awareness of having a mental illness?
   ☐ Full Awareness ☐ Moderate Awareness ☐ No Awareness ☐ Unable to Assess

3. What effect did the EIP have on helping the patient to maintain relationships with family?
   ☐ Exceeded Expectations ☐ Met Expectations ☐ Below Expectations
   ☐ Unable to assess

4. What effect did the EIP have on the patient's ability to engage in and maintain Friendships?
   ☐ Exceeded Expectations ☐ Met Expectations ☐ Below Expectations
   ☐ Unable to assess

5. What has your impression been of the EIP follow-up in terms of attention to patient needs?
   ☐ Very Good ☐ Good ☐ Average ☐ Poor ☐ Unable to assess

6. In your opinion, how well were your patient's symptoms managed by medication?
   ☐ Exceeded Expectations ☐ Met Expectations ☐ Below Expectations
   ☐ Unable to assess

7. What impact did the EIP have on the patient's overall ability to function in daily life?
   ☐ Exceeded Expectations ☐ Met Expectations ☐ Below Expectations
   ☐ Unable to assess

8. What was the overall treatment response?
   ☐ Exceeded Expectations ☐ Met Expectations ☐ Below Expectations
   ☐ Unable to assess

9. At what level was the patient functioning prior to the illness
   ☐ Independently ☐ Independently with some help ☐ Independently with much help
   ☐ Probably not Independently ☐ Definitely not Independently ☐ Unable to Assess

10. How might the patient be functioning after treatment including the EIP?
    ☐ Independently ☐ Independently with some help ☐ Independently with much help
    ☐ Probably not Independently ☐ Definitely not Independently ☐ Unable to Assess

11. Is this patient currently under your care? ☐ Yes ☐ No

12. What comments do you have on the EIP program?

    _____
    _____

Appendix L:
Early Intervention in Psychosis Program Focus Group Interview Guide

Early Intervention in Psychosis Program Focus Group Interview Guide

Moderator: Anne Neufeld
Assistant: Marje Lepnurm

Focus Group Introduction

Good morning and welcome.

Thank you for taking time to join our discussion about the Saskatoon Health Region (SHR) Early Intervention in Psychosis Program. Most of you know me, my name is Anne Neufeld, and I will serve as the moderator for today's focus group discussion. Rein Lepnurm, my PhD supervisor, is sitting in as an observer. Assisting me with recording and transcription is Marje Lepnurm. The purpose of today's discussion is to gather information about the Early Intervention in Psychosis Program from its inception in 1999 to the present and to discuss future directions. You were invited today because you have had an association with Saskatoon Health Region mental health services and, in particular, the Early Intervention program.

First, let's keep in mind that there are no right or wrong answers to the questions I am about to ask. We expect you will bring different points of view to the discussion. Please feel free to share your point of view even if it differs from what others have said. If you want to follow up on something that someone has said, if you want to agree, disagree, or give an example, feel free to do so. Don't feel you have to respond to me all the time. Feel free to have a conversation with one another about these questions. I am here to ask questions, to listen, and to make sure everyone has a chance to share. We're interested in hearing from each of you. So if you're talking a lot, I may ask you to give others a chance. And if you aren't saying much, I may call on you. We want to make sure we hear from all of you.

Marje and I will both be taking notes to help us remember what is said. We are also tape recording the session because we don't want to miss any of your comments. No names will be included in any reports. All information collected is confidential as to who provided it. My thesis and any subsequent publications will not make any attributions for quotes. We hope this encourages you to speak freely.

Everyone has been provided with a Program Logic Model for the SHR Early Intervention in Psychosis Program. Please use this as a reference point during our discussion.

Thank you again for taking the time to meet with us. We will honour your time by making sure we wrap up in the next 90 minutes, followed by lunch for those who are able stay. Any questions before we start?

Note: Briefly answer any questions.

Let's begin by having each person in the focus group introduce themselves.

Question #1: Tell us your name, how long you've been (or were) associated with Mental Health Services and/or the Early Intervention Program, and your role or relationship to the program.

Question #2: To start our discussion, please share how (and when) you first learned about the Early Intervention in Psychosis philosophy of care? What were your first impressions?

Question #3: What do you think are the strengths of this philosophy of care?

Question #4: What do you think are the weaknesses of this philosophy of care?

Question #5: Think back to when you first became involved with the SHR EIP program. What were your first impressions?

Question #6: Are the services which are being provided <u>currently</u> by the EIP those which were intended to be provided? Feel free to refer to the Program Logic Model.

Question #7: Is the appropriate organizational structure in place to maintain the EIP program? Give examples to support your response.

Question #8: Is the appropriate staff in place to offer the intended EIP program?

Question #9: We're interested in your impressions of how the Early Intervention Program has impacted clients' lives. Can you give some specific examples?

Question #10: What barriers have you encountered in trying to implement and operate the Early Intervention Program?

Question #11: What changes could be made to the Early Intervention Program that would allow your clients to benefit more from the program?

Question #12: Do you have any other ideas to make the SHR EIP program better?

Question #13: In your professional opinion, what new directions and challenges will Early Intervention in Psychosis Care face in the next 3 – 5 years?

Question #14: How will the SHR EIP respond to these new directions and challenges?

Question #15: Thank you for taking part in this focus group. Is there anything we should have talked about, but didn't?

Once again, thank you for joining us today. Your comments and insights have been very helpful. Once compiled, a summary of today's focus group will be provided to each participant. For those able to stay, a hot or cold buffet lunch is being provided upstairs. We hope you can join us.

Checklist for Focus Group Interviews

Advance Notice

_____ Contact participants by phone/e-mail two weeks (or more) before the session.
_____ Send each participant a letter confirming time, date, and place.
_____ Give the participants a reminder phone call/e-mail prior to the session.

Questions

_____ Questions should flow in a logical sequence.
_____ Key questions should focus on the critical issues.
_____ Limit the use of "why" questions.
_____ Use "think-back" questions as needed.

Logistics

_____ The room should be satisfactory (size, tables, comfort, sound, etc.).
_____ Arrive early.
_____ Check background noise so it doesn't interfere with tape recording.
_____ Place a remote microphone on the table (have a back-up microphone).
_____ Place the tape recorder off the table near the assistant moderator's chair.
_____ Bring extra tapes, batteries, and extension cords.
_____ Plan topics for small-talk conversation.
_____ Seat experts and talkative participants next to the moderator.
_____ Seat shy and quiet participants directly across from moderator.
_____ Serve food (following the session).
_____ Bring enough copies of handouts and/or visual aids (EIP flow diagram - program logic model).

Moderator Skills

_____ Practice introduction without referring to notes.
_____ Practice questions. Know the key questions. Be aware of timing.
_____ Be well rested and alert.
_____ Listen. Are participants answering the question?
_____ Use probe, pause, or follow-up questions as needed.
_____ Avoid verbal comments that signal approval.
_____ Avoid giving personal opinions.

Immediately After the Session

_____ Check to see if the tape recorder captured the comments.
_____ Debrief with the research team.
_____ Prepare a brief written summary.

References

Krueger, Richard A. and Mary Anne Casey (2000). Focus Groups: A Practical Guide for Applied Research. 3rd Edition, Thousand Oaks, CA: Sage Publications.

Modified from: Roger A. Rennekamp, Ph.D. and Martha A. Nall, Ed.D., University of Kentucky

Appendix M: Psychiatrist Comments - Thematic Analysis

Early Intervention in Psychosis (EIP) Program **Psychiatrist Comments - Thematic Analysis**		
Major Theme	**Sub-theme**	**Content**
EIP program performance	Service quality	"EIP certainly helped." "EIP provided good support to this patient." "Excellent program." EIP is "useful and helpful to both patient and psychiatrists." "Very good fit" with patient. "Appropriate support – effective." "Very good for this patient." "Very helpful in addressing acceptance of illness, compliance with medication, healthy lifestyle." Provided "good family support." "EIP made a very good effort and seemed to engage family well." "EIP made huge difference." "Support provided by the EIP was very valuable in the strong recovery of my patient. EIP was involved prior to my involvement." "With repeated relapses, (patient) deteriorated. EIP could not have an impact despite efforts."

	Inter-professional team	"Therapeutic alliance much improved." (RNP) "was an excellent source of support and provided excellent education re: lifestyle issues (e.g. not using drugs). The patient related well to (RPN) and respected (his/her) advice." "Continuity of nurse important. Psychiatric follow-up less so. Initial psychiatrist left on sabbatical leave at one year of treatment but returned one year later." "Dove-tailed nicely with McKerracher Program." "Most important – dedicated, resourceful, responsive community nurse." Important - "Consistency of nurse and psychiatrist – i.e. continuity, not passed from professional to professional." "Good connection with Community Mental Health Nurse." "Having a dedicated, enthusiastic community nurse was the most important."
	Patient flow	"Intake is a hindrance because some patients are in hospital. It would be helpful to be able to contact EIP independently to get an earlier, sometimes more informed opinion."

Patient prognosis and outcome	Response to medication	"EIP worked well but patient had poor response to meds." "Patient started improving after he was switched to clozapine."
	Employment and education	Patient "did not want to work which caused added stress." "After two years of treatment (patient) able to complete life skills course, and has part-time work." Patient was "able to return to school and repeated Math class successfully. Has motivation to attend Kelsey program for computer course." "Patient works part-time." Patient "doing fairly well academically." (Patient) "doing well in work placement." Patient is "presently in school."

	Compliance with treatment	"This patient had no insight, refused ongoing contact and became transient. This patient "needs support of EIP and excellent follow-up with care home for adherence to treatment." Prognosis is "guarded as patient is non-compliant." "Good (patient) response." Patient was "a very conscientious person who worked hard on understanding the illness and what he needed to do to succeed."
	Co-morbid substance abuse	"Regularly used substances and no regular treatment." "Patient had poor insight, continued use of alcohol and drugs." EIP "worked hard with a very difficult patient with suspicions, antisocial, and drug use issues in co-morbidity." "Dual diagnosis issues were resistant to treatment interventions."

	Social support	“Good support for patients with low social supports.” “Patient does well in Care Home and EIP. Not best (for patient) to live alone.” “The program worked very well to help a concerned anxious family become appropriately helpful and better adjusted.” Patient “needs to improve interpersonal relationships i.e. with his family, dating, etc.”

Appendix N: Focus Group Participants

Focus Group Participants

June 27, 2006

Rob Gentes, BComm
Manager of Mental Health Rehabilitation (including EIP) 2000 - 2005
Saskatoon Health Region

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Clinical Psychologist
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Early Intervention in Psychosis Program (1999 - 2005)

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Appendix O: Focus Group Themes

Early Intervention in Psychosis Focus Group Themes					
Theme	**Abbrev.**	**Theme-branch**	**Abbrev.**	**Sub-theme**	**Abbrev.**
Strengths of EIP Philosophy	ST	Improved model of care	IM	Increased family involvement	ST:IM:FI
				Team approach	ST:IM:TA
				Emphasis on education	ST:IM:ED
				Improved treatment compliance	ST:IM:TC
				Increased communication (interprofessional, etc)	ST:IM:IC
				Reduced stigma	ST:IM:RS
		Improved prognosis	IP	Retarded neurodevelopment deterioration	ST: IP:ND
				Reduced chronicity	ST:IP:RC
Weaknesses of EIP Philosophy	WK	Disease focus	DF	Challenges of diagnosis	WK:DF:CD
Impressions of SHR EIP Program	IP	Successes	SU	Staff skill and commitment	IM:SU:SC
				Reduced hospitalization	IM:SU:RH
				No wait list (quick response)	IM:SU:NW
		Challenges	CH	Lack of resources and sustainability	FI:CH:LR
				Staff burnout	FI:CH:SB
				Family conflict	FI:CH:FC
				Service fragmentation	FI:CH:SF
				Team dynamics	FI:CH:TD
				Co-morbidity	FI:CH:CM
				Inconsistent referrals	FI:CH:IR
Organization design and structure	OS	Unclear structure	US	Lack of integration	OS:US:LI
				Medical leadership	OS:US:ML
		Staffing	SM	Child and adult psychiatrists	OS:SM:CA
				Role of family physicians	OS:SM:FP
		Medical affairs	MA	Conflict and turf protection	OS:MA:CT
				Funding models	OS:MA:FM
Future directions	FD	Clarify organization structure	CS	Nested program	FD:CS:NP
				Renewed medical leadership	FD:CS:RL
		Inter-sectoral collaboration (e.g. school programming)	IC	Outreach team	FD:IC:OT
				Role of teachers and counsellors	FD:IC:TC
		Enhanced staffing	ES	Family worker	FD:ES:FW
		Education and communication	EC	Medical education	FD:EC:ME
				Website (family, patients, professionals)	FD:EC:WS
		Research and evaluation	RE	Assessment staff	FD:RE:AS
				Minimum data set	FD:RE:MD

Appendix P: Focus Group Sub-themes by Quality Dimension

Early Intervention in Psychosis Focus Group Sub-themes by Quality Dimension		
Quality Dimension	**Sub-theme**	**Abbreviation**
Structure	Team approach	ST:IM:TA
	Staff skill and commitment	IM:SU:SC
	Lack of resources and sustainability	FI:CH:LR
	Staff burnout	FI:CH:SB
	Service fragmentation	FI:CH:SF
	Team dynamics	FI:CH:TD
	Lack of integration	OS:US:LI
	Medical leadership	OS:US:ML
	Child and adult psychiatrists	OS:SM:CA
	Role of family physicians	OS:SM:FP
	Funding models	OS:MA:FM
	Nested program	FD:CS:NP
	Renewed medical leadership	FD:CS:RL
	Outreach team	FD:SP:OT
	Role of teachers and counsellors	FD:SP:TC
	Family worker	FD:ES:FW
	Medical education	FD:EC:ME
	Website (family, patients, professionals)	FD:EC:WS
	Assessment staff	FD:RE:AS
	Minimum data set	FD:RE:MD
Process	Increased family involvement	ST:IM:FI
	Emphasis on education	ST:IM:ED
	Challenges of diagnosis	WK:DF:CD
	Family conflict	FI:CH:FC
	Inconsistent referrals	FI:CH:IR
	Conflict and turf protection	OS:MA:CT
	Increased communication	ST:IM:IC
Outcome	Improved treatment compliance	ST:IM:TC
	Reduced stigma	ST:IM:RS
	Retarded neurodevelopment deterioration	ST: IP:ND
	Reduced chronicity	ST:IP:RC